A SYSTEMATIC EVALUATION OF PAEDIATRIC ALLERGY PATHWAYS IN THE WEST MIDLANDS

by

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ABSTRACT

This thesis considers the design of paediatric allergy services in the West Midlands (WM) region. It is presented in 3 parts: the first discusses a systematic review of allergy service delivery pathways across the UK and the rest of the world; The second quantifies the burden of paediatric allergy across the WM and compares it with the rest of the country using data from the health information network (THIN) database for primary care and the hospital episodes statistics (HES) database for secondary care. The final part ascertains the experiences of parents in the WM region who have accessed these services through a qualitative study and elicits parental preferences for these services using a discrete choice experiment.

The main argument put forth in this thesis is that services in a financially constrained environment should be planned efficiently and be responsive to the needs and preferences of the local population. A systematic way method to achieve this is presented along with recommendations for improving the efficacy and efficiency of paediatric allergy pathways in the WM region.

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TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

APPENDIX

1 INTRODUCTION

This thesis will evaluate paediatric allergy services in the WM region with a view to understanding the current pathways of service delivery, the challenges faced by clinicians and patients and proposing changes that can improve these services.

1.1 BACKGROUND

The NHS in the UK is a tax payer funded health care system which is free for all at the point of contact. The service embodies the notion of equity of health care- be it in terms of access, treatment availability or quality of services. The reality, is however, quite different. Services are often patchy, heterogeneous and, in the case of allergy, frequently non-existent. Terms such as 'allergy epidemic'[1], 'unmet need'[2], 'post code lottery' have all been used to describe the perceived urgency and inequity in the provision of these services in the UK.

There has been much interest in allergy services over the last two decades: eight reports by UK governmental institutions discussing the current state of allergy services between 2003 and 2013 [3-8], two reports from the World Allergy Organization (WAO) [9, 10], a further white book on allergy from the WAO recommending concerted action for improved patient care worldwide [11], and a report on allergy management in primary care across Europe [12] have all been published. Two prospective studies aimed at improving allergy service pathways have been initiated in the UK over the last two decades- one was a pilot scheme carried out in the Northwest of England [13] and another is a large NIHR funded project based in North west London [14]. The first project encountered many barriers and was unable to meet its target [13] and the second is yet to publish its final report.

The conclusion of most of these publications is the same: allergy services are not meeting the increasing demand placed on them. Specialist services are patchy, inadequate and are 'letting the patients down' [7]. More funding is needed to improve the number of available specialist allergists, specialist centres, trainee doctors in allergy and to improve primary care training for allergy.

Whilst these investments are important for service improvement, in the current reality of serious funding cuts to the NHS it is important to look at innovative and evidence based ways of improving efficiency of available services. This thesis explores the idea that improved service delivery can be achieved by planning services regionally through understanding the

demand placed on primary and secondary care services, learning from end user experiences of existing services and incorporating their preferences into future planning of services.

1.2 PAEDIATRIC ALLERGY SERVICES IN THE UK

Specialist allergy service provision in the UK is mainly provided by clinical allergists [15] and immunologists [16]. Given that there are very few centres across the UK with specialist availability, other medical specialists (such as respiratory physicians, dermatologists, ENT surgeons and general paediatricians) are often required to provide an allergy service to meet the growing demand. An assessment of NHS allergy service availability carried out in 2002 estimated the consultant availability for allergy in the whole of the WM region as being half of a full time equivalent consultant [15]. While this study grossly underestimated the contributions of immunologists [16] and specialists from other fields, it did highlight the severe shortage of allergy services in the UK. Many formal reports have since focused attention on the state of UK allergy services and the need for improvement [6-8, 17, 18], but concrete action has been lacking so far.

A questionnaire survey was carried out to examine the provision of paediatric allergy services in the WM in 2012 by Dr Martyn Rees, a consultant respiratory physician at the Royal Shrewsbury Hospital. Of the 16 trusts that were surveyed, 11 responded. All the responding hospitals provided paediatric allergy services, although only 63% of these were manned by personnel formally trained in allergy. 6 centres (55%) had access to nurse support, whereas only 3 of these were allergy specialist nurses. A third of the centres offered desensitisation or immunotherapy services for children. Only 2 centres had access to dietician support on the same day [personal communication with Dr.Rees; data included with permission]. Figure 1.A in the appendix shows a map of the WM highlighting NHS hospitals that provide paediatric allergy services.

1.3 AIM AND OBJECTIVES

The aim of this study is to evaluate paediatric allergy services in the WM region.

The study objectives are:

1. To understand the modes of delivery of allergy services worldwide; to explore the challenges, success stories and the future directions for service delivery
2. To understand the current demands placed on NHS services due to paediatric allergy in a) the UK or England and b) the West Midlands (WM)
3. To understand end user experiences in relation to paediatric allergy services in the WM
4. To ascertain end user preferences for these services in the WM

The implications of the research findings on pathways for paediatric allergy service delivery in the WM will be considered.

1.4 OVERVIEW OF THE THESIS

Chapter 2 addresses objective 1 by presenting a systematic literature review of pathways for the delivery of allergy services worldwide [19].Very few prospective studies were identified in this review, none of which included a control group. Most of the publications included in the study were from the UK, confirming an intense interest in allergy service re-organisation within the country. A copy of the publication related to this work is included in the appendix (7.A).

Chapters 3 and 4 address objective 2 of the thesis.

Chapter 3 is dedicated to the analysis of the health information network (THIN) database, a primary care database for the UK NHS. Trends in the UK incidence and prevalence of common childhood allergies and related conditions are presented. Data from the WM are specifically explored to understand whether or not there are regional differences in allergy epidemiology which can be used to inform service provision.

Chapter 4 reports the analysis of a secondary care database, the Hospital Episodes Statistics (HES), which includes data on all admissions into NHS hospitals in England. Data relating to emergency admissions and to elective admissions (specifically those related to immunotherapy treatments) are presented.

Chapter 5 describes a qualitative study carried out to understand experiences of parents who have accessed primary and secondary care paediatric allergy services for their children within the WM region, thus addressing objective 3 of the thesis. 18 parents recruited from two different secondary care paediatric allergy centres were interviewed.

Using the themes identified from Chapter 5, a discrete choice experiment (DCE) was planned to ascertain parent preferences for paediatric allergy services in the WM. This is discussed in Chapter 6. Around 280 parents from the region completed a carefully designed questionnaire aimed at understanding the magnitude of preference for the choices provided in the study. This chapter addresses objective 4 of the thesis.

Finally, Chapter 7 discusses the overall conclusions from the thesis. Findings from the various elements of the work are viewed together to provide a coherent view of paediatric allergy services in the UK and the WM. Recommendations are made for the improved delivery of these services in the WM and areas for future research are highlighted.

2 A SYSTEMATIC REVIEW OF PATHWAYS FOR THE DELIVERY OF ALLERGY SERVICES

In the previous chapter, the issues relating to allergy service provision in the UK and the WM were touched upon. Given that an increase in allergy prevalence is not likely to be UK specific issue, a review of published literature was carried out to understand delivery of services elsewhere in the world. This chapter describes the scope, methods and results of this literature review. The aim of this systematic review is to assess published approaches to allergy service delivery. The objective is to identify and appraise these publications to gain an understanding of the advantages as well as challenges associated with these service pathways; and also to explore current ideas regarding the future direction for these services.

2.1 INTRODUCTION

The United Kingdom (UK) has amongst the highest rates of allergy and related diseases in the western hemisphere [20] and there has been a steady increase in the prevalence, severity and complexity of allergic disease in the last 2-3 decades [21-24]. It is estimated that 30% of all adults and 40% of children in the UK will be affected by allergy related conditions during their lifetime [18]. Nevertheless, allergy services have remained 'woefully poor' [18] with very limited and patchy specialist service availability. This shortfall in service availability and the inherent heterogeneity of limited available services has been the focus of multiple expert body reviews in the UK, which have called for increased investment in allergy management and for re-organisation of allergy services [6-8, 17, 18].

One of the major barriers to service planning in allergy is the lack of political engagement and reluctance to allocate funds from the local budget for improving allergy services [13, 25]. Allergy is not generally perceived as a serious condition with major implications for health and quality of life. There is a growing body of evidence to the contrary, however. It is now established that children with food allergies are more anxious than those with insulin dependent diabetes, and tend to have overprotective and very anxious parents [26]. This is also true of adolescents with a history of anaphylaxis [27]. Allergy and related conditions are estimated to cost the UK NHS about £1 billion per year [28]. Productivity losses associated with allergic rhinitis in the USA were higher than those due to stress, migraine and depression [29]. Studies have shown that effective allergy services can not only improve quality of life, but can also be cost-saving [30, 31]. Hence there is an urgent need to impress upon policy makers the importance and wisdom of investing in the improvement of allergy services.

There is currently no agreement on how allergy services should be structured. In the UK and Europe, primary care practitioners diagnose and manage the majority of individuals with allergies [25] whereas in Australia and the USA, specialist services face the bulk of allergy care [32]. Allergy service delivery by non-physician practitioners such as pharmacists and dieticians, whilst possible, is not optimally utilised [8]. Various pathways have been

suggested and are being tested [13, 14, 33]. However, it is not yet clear whether any particular model of service delivery may be preferable to the others.

The aim of this systematic review is to assess published approaches to allergy service delivery. The objective is to identify and appraise these publications to gain an understanding of the advantages as well as challenges associated with these service pathways; and also to explore current ideas regarding the future direction for these services.

2.2 METHODS

The Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines were followed in conducting this systematic scoping review. The PRISMA checklist is included in appendix Table 2.A

2.2.1 Data sources and search strategy

A systematic search of the literature was carried out to identify articles related to allergy service pathways in humans. Search terms included allergy, eczema, care, service and pathway (See Appendix Table 2.B). MEDLINE, EMBASE, HMIC, CINAHL, Cochrane, DARE, NHS EED, INAHTA databases were searched for the purposes of this review. An explanation regarding these databases and their scope is shown in Appendix Table 2.C.

Searches included publications indexed until the 4th of October 2016. In order for the Medline® searches to be relevant, we stipulated that two papers selected *a priori* [9, 15] should be identified in the search. References within the publications identified as relevant were individually examined to identify more articles of interest. Publications citing the chosen articles were also carefully examined for relevance.

2.2.2 Selection of literature

After discarding duplicates, the title and abstract of the articles were examined for relevance. Where these were not informative, the full text of the publication was reviewed. Articles were included for review if they discussed pathways for the delivery of allergy or eczema services. Publications which reported opinions, conference abstracts, case reports or

case series were excluded. Non-English language articles were not included in the review. Asthma service pathways were also not considered. One of the researchers (LD) carried out the searches with help and advice from an information specialist from the University of Birmingham. LD screened all the articles as per the pre-determined criteria. A total of 50% of the unselected articles (25% each) were reviewed independently by the thesis supervisors (TR and CC). Disagreements, if any, were resolved through discussion and consensus.

The PRISMA flow chart for selection of articles is shown in Fig.2.1

2.2.3 Data extraction and analysis

The data extraction form was initially piloted using a few publications. Appropriate modifications were made after discussion with supervisors and colleagues before the full extraction was started.

Data was extracted by LD using the finalised extraction table (Appendix Table 2.D). For each publication, the author, year of publication, geographical region of interest, type of study (report, discussion, consensus etc), study design (prospective, retrospective, cross section), treatment pathway (primary, secondary or both), principal findings and key recommendations were extracted.

Most of the articles were descriptive and hence the analysis followed a narrative synthesis. This is a common approach in reviews of very heterogeneous studies which aim to describe and scope an area of interest [34]. Since the objective of the report was to explore options for service delivery, the review was designed to be inclusive. Publications were, therefore, not excluded based on quality criteria but were described and critiqued briefly as appropriate. Given the nature of the publications, the review aimed at mapping the current literature and understanding the type of evidence available in this area (i.e. delivery of allergy services).

2.3 RESULTS

The database search identified 351 articles of which 158 were duplicates. An additional 12 articles were included following reference and citation searches. After consideration of the

title and abstract, a further 142 articles were excluded and a total of 63 publications were screened thoroughly for their relevance to the review. Figure 2-1 shows a flow diagram of the papers screened, identified, retained or excluded at each stage, and the reasons for exclusion of articles [35].

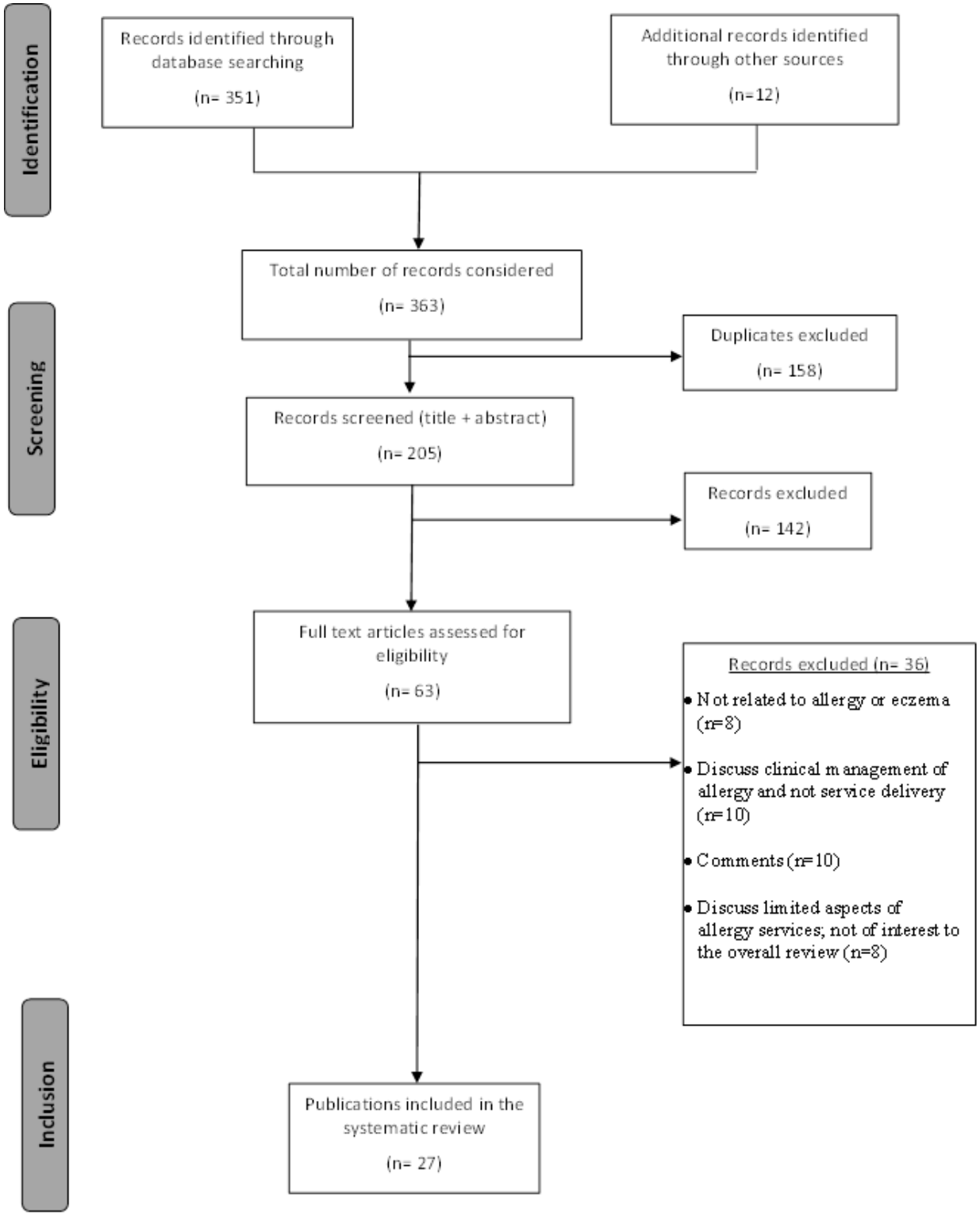


Figure 2-1: PRISMA flow diagram for the systematic review

Twenty seven publications were included in the final review and these are summarised in Appendix Table 2.D. Only three publications describe prospective data collection alongside service re-organisation [13, 33, 36]. There were no eligible prospective, randomised controlled trials identified.

Seven of the publications discussed allergy services in other parts of the world [9, 12, 25, 33, 37], whereas the rest are focused specifically on services in the UK. Of the 20 UK papers, eight are reports published by governmental organisations discussing the state of allergy services in the UK [3-8, 17, 18]. One of these reports provides a brief overview on aspects of allergy services in other European countries (Germany and Denmark) [18]. Another summarises experiences following the establishment of a pilot allergy service in the North West of England [13].

Re-organisation of primary care was addressed by seven publications, secondary care services were the focus of six articles, while four discussed both levels of care. All eight government reports (Appendix Table 2.D) discuss all aspects of service delivery. Three studies discussed the use of digital technology based interventions for allergy [38-40]; one of these retrospectively evaluated such a service [40]. Findings, statements and recommendations about allergy service pathways from the included papers are reported in Appendix Table 2.D and are synthesised thematically below.

2.3.1 Primary care services

Primary Care Practitioners (PCPs) in allergy service delivery

PCPs are the first line providers of health care in most countries around Europe [12]. They are well placed to provide diagnosis, to manage mild and most of the moderate allergic conditions, as well as to refer individuals with complex and severe allergies to specialist services [12]. Many publications have identified that the training offered to PCPs in allergy currently is inadequate [6-8, 13, 17, 18, 41, 42]. The current inadequacies in training and the need for better information provision as well as structured training programmes for PCPs in allergy were reinforced in studies from Scotland, Italy and Spain [25].

It was argued in two European publications that a model of care which is centred on specialists or consultants is untenable in allergy [12, 25]. In public funded health systems such as the UK where PCPs assess and manage the majority of patients, the burden placed by allergy and related conditions on primary care could be significant. For example, it was estimated that allergy accounts for 8% of all general practice consultations in the UK and that up to 11% of the total drugs budget is spent on allergy related medication (including asthma and eczema) [18].

One article considered the lack of access to secondary services as allergy's 'greatest unmet need' [25]. Referral times to specialists vary considerably across Europe from over 3 months in some tax funded health systems [6, 8, 25, 37] to as little as one week when specialists can be accessed privately [25]. Across Europe organ specialists are generally more readily accessible to PCPs than allergists [25]. In a UK based survey of over 480 PCPs, 81.5% of the 240 PCPs who responded felt that the NHS allergy services were poor and 80% felt that secondary care provision was inadequate [41]. These practitioners were reported as being especially anxious about treating children with food allergies, although most felt quite confident about managing common allergic conditions such as anaphylaxis, urticaria, allergic rhinitis and drug allergy [41].

PCPs with an interest in allergy

Two publications specifically discussed a second tier service for allergy within primary care [25, 43]. Such an arrangement was also proposed by the House of Lords report [18]. In the UK, a prospective evaluation of a General Practitioner with Special Interest (GPwSI) facility in allergy revealed that the service was well received, reduced the levels of secondary care referral and had a potential for cost savings [36]. Further, in this study, PCPs appeared to refer patients more readily to the GPwSI than to secondary care [36]. However, establishing these services would need a well-defined process of accreditation and specialist mentorship [12] which is difficult to achieve in most countries given the current severe shortage in the availability of specialists across Europe [9, 12].

Non-physician services in Primary care

Non –physician services for allergy were specifically discussed by 6 publications in this review [4, 6, 8, 18, 42, 44]. Most of the articles discuss the under-utilisation of these professionals in allergy and suggest that there is a scope for better training of nurses, pharmacists and dieticians in allergy. Depending upon the extent of training and the competencies achieved, nurses can be involved with testing, diagnosis and management of patients with allergy [42].

Some authors felt that pharmacists could, if adequately trained and sufficiently supervised, provide information to patients regarding techniques for using devices such as nasal sprays, eye drops, adrenaline auto-injectors as well as inhalers for allergy and related conditions [18, 42]. They can help patients choose over the counter medication for allergy judiciously. They can also be trained to advice individuals on the need for consultation with their PCP, where appropriate [8]. The House of Lords committee suggested that all pharmacists be formally trained in allergy to ensure that high quality advice is provided to all patients [18]. This committee also reported concerns from clinicians regarding availability of unvalidated tests over the counter for allergies in some establishments [18]. There are, however, no publications to-date formally assessing the role of pharmacists in the diagnosis and management of allergy.

Barriers to providing optimal allergy care in the Primary care sector

In most countries, the lack of leadership and support offered by a stable, well-staffed specialist service was identified as one of the main barriers to improvement of primary care services [4, 6, 7, 17, 25].

Several authors were also concerned that PCPs do not receive structured instruction in allergy during their training and very few are familiar with guidelines for management of allergic disease [6-8, 15, 25]. The House of Commons health committee highlighted the lack of allergy knowledge in primary care as "…..one of the principal causes of distress to patients" [17]. Some articles have specifically highlighted the significant gaps in allergy

training at the undergraduate and postgraduate levels, as well as inadequate continuing medical education programmes for PCPs in allergy [6, 7, 12]. This was identified as leading to inappropriate referrals to a range of specialists [13], lack of engagement with secondary care services for allergy, delays in diagnosis and starting appropriate management [6] and, sometimes, to inappropriate management [15]. All these issues resulted in poor patient experience but also cause a significant wastage of scarce health care resources [6, 7]. A retrospective review of the patients at a secondary care allergy clinic in Sussex showed that at least 42% of patients were referred for conditions that could have easily been managed in primary care, had the PCPs been appropriately trained [45]. An Irish study also suggested that increasing awareness of common allergic conditions amongst PCPs can significantly reduce referrals to specialists [46].This suggestion was reinforced in UK government reports [6-8, 17] and other studies [13].

2.3.2 Secondary care services

Availability of specialist services

A publication by the World Allergy Organisation (WAO) has suggested that there is a great degree of heterogeneity in access to specialist allergy services across the world [9, 37]. For example, the number of certified allergy specialists per head of population range from 1:25 million (in Malaysia) to about 1:2 million (in the UK) and 1:16,000 (in Germany) [9].

Heterogeneity in specialist training has also been highlighted [9, 15] with only a few countries providing certified courses to practitioners in allergy. Experts point out that whilst there has been very little increase in availability over the last few years, the demand for specialist allergy services has been steadily increasing [7]. A worldwide study by the WAO showed that paediatric allergy services are particularly underserved and children with allergic problems are generally managed by general paediatricians with or without formal allergy training [9]. This study also found that in many countries children may be managed by specialist adult physicians without appropriate paediatric training [9]. Specialist training pathways for allergy vary markedly worldwide. In countries such as the UK, formal

certification procedures in either allergy alone or in a combination of allergy and immunology exist. Similarly, in the United States, allergists/ immunologists should have passed a professional examination taken after 2 years of structured speciality training. In other countries, allergy may be included as a sub-speciality in general internal medicine or paediatrics training [9]. In Germany, for example, allergology is considered a subspecialty of dermatology [18]. In the UK, the British Society for Allergy and Clinical Immunology (BSACI) has estimated that 90% of secondary care in the UK is provided by allergists and immunologists [5]. A study carried out in the UK has shown that immunologists, who have formal training in allergy, provide allergy care to 32 million individuals in the UK [16]. Some authors have pointed out that immunologists are indeed the sole providers of allergy services in parts of the UK [4, 16]. Other specialists such as those with primary qualifications in ENT, respiratory medicine or dermatology also contribute to the delivery of allergy services in many countries [9] including about 10% of the total secondary care for allergy in the UK [5]. Even if this broad definition of allergy specialists were to be accepted, many experts feel that allergy services remain inadequate in most countries in the face of increasing demand for these services [9, 17, 37].

Specialist centres for allergy

Some authors propose the 'hub and spoke' model [6, 17, 18, 37] which involves the establishment of supra- regional tertiary allergy centres (or hubs) which can support regional secondary and primary care centres (the so-called spokes) for delivery of specialist services. A few suggested that these centres should be manned by consultant adult and paediatric allergists, nurse specialists as well as adult and paediatric dieticians while providing facilities for training at least two specialist registrars in allergy [6]. Others felt that these should be multi-specialist centres (e.g. chest physician, dermatologist, ENT specialist, paediatrician in addition to an allergist or clinical immunologist) that are built on existing expertise of the local area and serve as 'clusters of expertise' [18]. In some countries, these centres would typically be University Hospitals which would receive referrals only from specialists [18].

Whatever their composition, most agree that these centres could serve to educate and support primary and secondary care physicians in the region [6, 17, 18]. It was suggested that they had a potential to serve as centres of excellence for adults and children with complex and severe allergies; establish a good, working network between organ-based specialists, generalists and allergists and serve to improve the overall provision of allergy services in the region [18].

Some experts point out that the existing shortage of specialists in allergy would be a barrier to the development of such centres [7, 47]. A pilot study carried out in the North West region of England found that developing large tertiary centres would not be practical in regions with large cities in close proximity to one another [13]. They may not be cost-effective for many regions within the UK [7].

The House of Commons Health Committee has pointed out that there are no clear data to suggest that specialist centres improve clinical outcomes in allergy management [17, 48]. Indeed, even in countries like Germany with a relatively high proportion of allergy specialists per 100,000 population, the numbers of emergency admissions for allergy remain high [9]. The North East England pilot study found that the lack of confidence amongst primary care physicians while dealing with patients with allergy led to poor referral practices [13]. As a consequence, management of simple conditions took up a disproportionate amount of specialist time and resources while individuals with complex allergies faced long waiting lists as well as inappropriate referrals to other specialists [13].

2.3.3 Future direction for services

Whilst efforts are being made to improve allergy education at the undergraduate and post graduate levels, there has been a focus also on the improvement of training of current practitioners. The Royal College of Paediatrics and Child health has developed care pathways for children which define core competencies for all those involved in managing allergies and related conditions; these are freely accessible online [49]. These are UK focused but

potentially can be modified to suit other countries. Such pathways embrace the current heterogeneity in service delivery whilst attempting to raise standards.

The 'Hub and spokes' model was trialled in the UK with mixed results [13]. The authors suggested that new services should be tagged onto existing pathways and also stated that a model of visiting specialists in secondary centres would be more welcome in some areas than the establishment of large tertiary centres [13]. It was also suggested that models of good care can vary from one region to another [7, 13].

There have been recent publications regarding the use of digital technology in the provision of allergy services [38-40]. One addresses the use of telemedicine in improving communications between primary and secondary care in order to improve adult allergy pathways within the NHS [38]; whereas another makes a case for clinical trials using information communication and technology (ICT) in management of allergic rhinitis in Europe [39]. A publication from Ireland reported on the use of an email communication system, which received an average of only 4 enquiries per month over a 12 month period. Although it was rated useful by 100% of the non-specialists who responded to the survey carried out by the researchers (response rate of 35%), this communication system did not reduce referrals to the specialist allergy services [40].

There has been a lot of interest lately in the "Finnish model" of service re-organisation. This re-structuring exercise takes inspiration from the successful interventions for asthma in Finland [50]. Whilst acknowledging the differences between asthma and allergy as well as emphasising the need to understand and improve tolerance to allergens, the architects of this model hope to use the existing asthma infrastructure to improve services for allergy sufferers. They suggest that increased initial outlay aimed at preventing allergies and changing attitudes towards health alongside improving service delivery can reduce the cost and burden of allergic disease in the future [33]. The results of this experiment are currently awaited.

2.4 DISCUSSION:

2.4.1 Principal findings of the review

This systematic review aimed to identify and discuss various pathways that are relevant to the delivery of allergy services. There were large gaps in literature pertaining to services in countries with high rates of allergy (such as Australia, New Zealand, United States) [20, 51] as well as very populous regions of the world including China, India, Brazil and the whole of Africa. There were virtually no publications from low and middle income countries. In addition, there was a lack of well-designed studies in this area with only three prospective studies identified [13, 36, 50]. None of the studies included a control group. Two of these publications [13, 33] describe service re-organisation on a large scale with direct involvement of the relevant health ministries.

There is clear evidence from literature that allergy services across the world have not kept up with rising demand. The 'allergy epidemic' [1] has surprised unprepared health systems globally. There has been failure on the part of governments and fund holders to acknowledge the rapid rise in allergies. Given that there are no signs of abatement in the observed increase in allergies worldwide [23], it is conceivable that the demand on services is set to increase even higher over the next few years.

The psychosocial impact of these conditions is often overlooked. For example, atopic individuals experience significantly worse memory and cognitive ability during allergy season [52]. Children with eczema report higher levels of anxiety and depression [53]. In addition, these conditions currently place an inordinate financial burden on healthcare services [30, 54, 55]. Urgent and effective measures are therefore needed to cope with the problem.

About three-quarters of the eligible publications (20/27) are from the UK which suggests that there has been a lot of interest here in investigating the extent of the supply gap in allergy services over the last 15 years. It is striking, however, that whilst most of these reports describe the problems with service delivery and suggest some solutions, none seem to have addressed the problem in a structured manner. There has been no response to the UK

Department of Health's request for reliable baseline data on needs of the population, costs involved in service re-organisation and the details of skills and competencies of the existing workforce in order that future services can be planned [3-5].

Primary care services are key to optimal management of allergy. Appropriate management after good history taking and specific testing can easily be achieved in primary care for a majority of patients. Referral to specialist centres can be limited to only complex patients needing multi-disciplinary input or those that need desensitisation therapy. However, a UK survey has shown that PCP confidence in managing allergies in children [41] and initiating referrals appropriately is limited. Although PCPs in this particular survey felt confident about managing adults, studies have shown that most individuals referred to secondary care could have been managed effectively in primary care [13, 46, 56]. This serves to highlight the inadequate training received by PCPs in allergy at both undergraduate and postgraduate levels. This leads to not only poor patient experience and outcomes but is also more expensive for the health service providers.

A paucity of specialists in allergy encourages PCPs to refer patients to specialists who are only able to deal with individual manifestations of the condition (e.g. respiratory physicians for allergic asthma; ophthalmologists for allergic eye disease). Organ based specialists play a very important role in the management of allergic disease. Indeed, in some instances (e.g. children with very severe disease), their input is essential. However, specialists trained specifically in allergy management can provide clinically effective and potentially cost effective services by intervening across several of these conditions for most patients[6].

Scarcity and inequity of specialist allergy services was a recurring theme in many articles worldwide. Although numerous publications have made a compelling case for more specialist centres [6, 7, 9, 15, 17, 18], these have not been forthcoming. Many factors appear to contribute to this apparent inertia [7]- the important ones being lack of adequate central funding to increase training numbers for specialists, lack of interest in allergy services amongst fund holders [13], lack of clarity regarding the role of various specialists involved

[7]. Another important issue is the lack of formal training programmes in allergy in many countries [9]. This not only blights the care of individuals with allergy in these countries, but also prevents the speciality being taken seriously by decision makers. In the case of the UK, lack of clinical codes to measure allergy activity and disagreements between the two main specialist groups that provide allergy services (allergists and immunologists) are also important issues [3]. Further, in the UK, the lack of specialist services and poor referral practices within primary care have resulted in unreliable waiting list data, which are often used as a surrogate marker for need within the NHS [4]. This has proved to be a barrier for further investment in services [3].

It should be noted that there are no published data that support the success of large, tertiary centres. Nevertheless, it is conceivable that centres which treat large volumes of individuals will provide better outcomes for complicated patients [57]. However, the lack of confidence amongst primary care physicians while dealing with patients with allergy leads to poor referral practices leading to long waiting lists as well as inappropriate referrals to other specialists [13].

There have been many encouraging advances in allergy service re-organisation in the UK and beyond. New multi-consultant allergy centres were created in the North West of England as per the recommendations of the House of Lords report into allergy services [18]. This service development encountered many barriers including non-engagement of local commissioners, non-availability of appropriately trained staff, and poor coding practices [13]. Nevertheless, the project was successful in improving networking amongst specialists across the region, improved clinical governance including audit, better regional education programmes for clinical staff and patients in allergy [13]. There was an opportunity during the course of this project to prospectively collect data on patient experiences and outcomes, which was unfortunately missed.

The heterogeneity in specialist training across Europe is also being addressed with the introduction of the European Examination in Allergology and Clinical Immunology since

2008 by the European Academy of Allergy and Clinical Immunology (EAACI). The aim of this examination is to "raise standard of allergology and clinical immunology in Europe" and to "facilitate the exchange of young people trained in Allergology and Clinical Immunology" in Europe [58].

The Finnish allergy model is based on the very successful restructuring of asthma care in Finland [59] and is now being adapted to the management of other chronic conditions [60]. In Finland, the model has been altered to incorporate the complex and heterogeneous nature of allergy but it essentially builds on the existing infrastructure developed for the asthma programme [50]. The Finnish allergy plan is an ambitious project that aims to reduce the burden of allergic disease by improving tolerance and reducing the emphasis on allergen avoidance in affected individuals. The objective is to help alleviate the psychosocial aspects of allergy whilst improving services provided to these persons [33]. Aspects of this plan have also been adopted by Norway [61] and by health authorities in North West London as well as Sheffield [62]. Preliminary results from the London project are very encouraging [14, 63, 64]. More data are awaited to ascertain whether the project has been successful and also if this success can be emulated in other regions.

2.4.2 Strengths and limitations of the review

The strength of this review is that it provides a systematic and comprehensive look at the reported current provision of allergy services across the world. There are some limitations mainly due to paucity of information from most countries, including some with relatively high allergy incidence and prevalence, regarding available services. Most of the literature is UK based and hence generalisability of data to other countries, especially those without publicly funded health systems may be limited. In addition, there were very few well planned prospective studies and no controlled studies in this area. Most of the included studies had little empirical data and therefore a formal quality assessment of the publications was not carried out. Studies not reported in the English language were excluded.

2.4.3 Strengths and limitations in relation to other studies

This review is the first to comprehensively review all the published reports and journal articles on allergy services. This review, in concurrence a previous UK review [65], found that prospective studies in the area were lacking and that there were no data objectively comparing different levels of service delivery (e.g. primary care versus secondary care).

2.4.4 Future research

There is a need for data on service pathways from across the world, especially from countries with a high burden of allergic disease so that the extent of the problem can be identified and lessons may be learnt from successful models. Prospective data aimed at estimating the costs and outcomes of service pathways are especially important. To ensure that a service is successfully re-organised, it is important to understand the needs of the local population, their preferences for services and to estimate costs and benefits of the possible service pathways.

2.5 CONCLUSIONS

There is a consensus that allergy services across the world are inadequate to meet the rising demand. There is a high degree of heterogeneity and inequity in the availability of services across the world. Untreated or poorly treated allergic conditions can have a high psychosocial impact on individuals and can place a substantial economic burden on healthcare services. Allergy training does not feature adequately in the current undergraduate and postgraduate medical curricula, which is adversely affecting patient care at all levels, especially in primary care. Primary care services are affected by poor training of practitioners and by poor access to specialists. Specialist services are hampered by the non-availability of appropriately trained personnel and poor referral practices from primary care (where applicable) which lead to long waiting lists and poor overall patient care. There is currently no clear consensus on how services should be structured, although the Finnish model of service re-organisation has shown significant promise. Political engagement and patient empowerment are important to the success of these projects.

Having carried out a review to look at the allergy pathways globally, the next step was to look at the performance of NHS allergy services in the UK and the WM. In order to assess the demands placed on the NHS due to allergies, an analysis of routinely collected NHS primary and secondary care data was planned. The next chapter describes and discusses the results from analysis of the health improvement network (THIN) database, whereas Chapter 4 discusses the findings from analysis of the hospital episodes statistics (HES) database.

3 ANALYSIS OF HEALTHCARE DATABASES- THE HEALTH IMPROVEMENT NETWORK (THIN) DATABASE

In the previous chapter, pathways for delivery of allergy services around the world were reviewed. It is important to estimate the demands placed on available services and to understand the incidence and prevalence trends of allergies in order to effectively plan future services. An analysis of primary and secondary care databases was therefore planned for this thesis. This chapter will discuss findings from the analysis of primary care data using the health information network (THIN) database.

3.1 INTRODUCTION

One of the findings of the literature review was that there is considerable heterogeneity in the availability of paediatric allergy services across the UK. Various reports commissioned in the UK proposed solutions to improve these services nationwide [6, 7]. Important as these improvements may be, health services in the UK are now commissioned by Clinical Commissioning Groups in order to best serve the needs of the local population [66]. In addition, the distribution of expertise is quite unequal across the UK [47], suggesting that there needs to be some flexibility in adapting these solutions regionally. The Department of Health has suggested that regional allergy services could be structured based on the needs of the local population and availability of regional expertise [3].

There are no published data exploring the regional differences in the epidemiology of allergy and related conditions across the UK. Indeed, it is not clear if and how the allergy needs of children in the WM differ from those in the UK as a whole. Therefore, an estimation of the demand placed on primary and secondary NHS services in the West Midlands (WM) and more broadly in the UK (or England) due to paediatric allergy and related problems was planned for this thesis. Contrasting the estimates for WM with those obtained from the entire nation would help provide an understanding about the issues unique to the region, if any, which may help in planning regional services. This would serve as a good starting point for planning effective and efficient care pathways for the region.

In this chapter, data from the Health Information network (THIN) database is used to estimate the burden placed by paediatric allergy and related conditions on primary care practitioners in the UK. The burden of disease on WM primary care will also be discussed.

3.2 BACKGROUND

It has been shown that the incidence and prevalence of allergies worldwide is increasing [20]. Indeed, data from the International Study of Allergies and Asthma in Childhood (ISAAC) suggests that there has been a rise in the prevalence of parent-reported asthma,

rhinitis and eczema amongst 6-7 year old and 13-14 year old children globally over an average of 7 years (range: 5-10 years; SD:1.2 years). The ISAAC study used standardized diagnostic questionnaires [67] delivered to participants at certain time points. Whilst the trends in the various ISAAC respondent countries (between 37-56 countries overall in ISAAC I,II and III studies) varied markedly, the overall trend has shown an increase in the prevalence of these conditions, especially in the 6-7 year old age group [68]. However, data from individual countries present a more mixed picture [69-72].

The incidence and prevalence trends in allergies have been studied intensively in the UK in the last decade [22, 73-75]. An important factor driving this interest is the relatively easy access to large datasets that can provide a wealth of information regarding these (and other) conditions while maintaining patient confidentiality [76]. The advantage of investigating national health datasets is that they are representative of the population of the country as a whole and the results obtained can be applicable to all regions of the country. The data can be used to assess the scale of the problem, and to identify areas where investments can be targeted to obtain maximal improvement in patient care. Various databases providing health related information are available in the UK [76]. Some of these are outlined in Appendix Table 3.A.

Allergy related epidemiological data have been reported from other sources such as population surveys in selected geographical areas [77] or from evaluation of at-risk patients (e.g. scrutinising medical records of patients attending allergy clinics [78] or assessing atopy in children with eczema [79]) . Whilst such information is useful in understanding the health needs of a selected population, the data are not generalisable. In addition, direct comparisons between such data from different regions are often not possible since there may be differences in definition of disease condition, mode of data collection and also demographic differences in the populations studied [77, 80]. More recently a large scale, multi-country, Europe wide study has been initiated to better understand the prevalence of childhood food allergies [81]. Children are being followed up from birth (in some cases, antenatally) to prospectively

evaluate the prevalence of specific food allergies using validated questionnaires and double blind placebo controlled food challenges [81]. While this study boasts the most robust protocol for evaluation of food allergy prevalence to date, the generalisability of these data to all regions of Europe is debatable.

We set out to understand the burden placed by paediatric allergy on the NHS in the UK and also in the WM by interrogating two large databases comprising of routinely collected health data - The Health Information Network database or THIN (which is a primary care database) and the Hospital Episodes Statistics or HES database (a secondary care database). These datasets are large, fairly uniform across the entire user-base and reflect everyday care provided within the NHS. THIN and HES databases differ from each other in many aspects. The main differences are outlined in Appendix Table 3.B. This Chapter will be dedicated to the discussion of THIN data analysis. Analysis of the HES database will be discussed in Chapter 4.

3.3 THE HEALTH IMPROVEMENT NETWORK DATABASE (THIN)

3.3.1 Introduction

The Health Improvement Network (THIN) database is a large anonymised primary care dataset containing information from UK general practices. It was launched in 1995 and was designed to enable record keeping for the benefit of patients and clinicians. The database reflects everyday care provided to individuals within the participating general practices [82]. These practices use Vision® computer software and data collected are anonymised and made accessible for research via the company IMS health.

The database currently includes information from 587 GP practices across the UK, covering a total of over 12 million patients (about 3.6 million active patients), who represent 5.67% of the whole UK population [83]. These patients are representative of the UK population by age, gender, medical conditions and death rates adjusted for demographics and social deprivation [82].

3.3.2 Data captured within the THIN Database

At each appointment, the primary care practitioner records reason for consultation, diagnosis, main symptoms and signs and, where applicable, details of prescription, laboratory tests, demographic details (such as height, weight, blood pressure). The data are anonymised by removing identifiers such as name, address, post code, date of birth of the patient and the name, address and post code of the practice. Free text is also removed as this often contains patient identifiers. Data are cleaned by removing duplicates and made available for research. In the THIN database, medical conditions are identified using Read codes [84] (so called since they were developed by Dr. James Read- a UK primary care physician). These codes are dynamic i.e. are regularly updated based on user feedback and experience [84]. The codes mainly consist of alpha numeric identification of the condition in 4 character codes (or the 4-byte version of code) or, more recently, in 5 character codes (5-byte code or Version 2) [85]. The earlier versions have now been merged into a unified Version 2, which is currently in use within the UK.

Read codes have a broader remit than other diagnostic codes (such as ICD codes) and can be applied for recording symptoms and signs, ethnicity, socio-economic status, administrative items (such as invitation for screening tests), laboratory tests and results. Over 100,000 codes are currently available and are used by all practices using the Vision software.

It is important to note that the health data obtained from the THIN database are physician identified and demand driven (i.e., only include individuals who choose to see their GP for the given ailment).

3.3.3 Organisation of data within the THIN Database

The THIN database is continually updated (usually once every 3 months) and the consultations are linked to individual patients.

The data collected are organised into different records linked to every individual patient namely patient records, medical records, therapy data and additional health records as shown in Figure 3-1.

In addition to these data, THIN includes Townsend score, which is a socio-economic indicator derived from the patient's post code [86]. The population is divided into quintiles with the least deprived 20% receiving a score of 1 and so on. Thus, higher scores represent greater levels of deprivation. Individual level socio-economic indicators are not available within this database.

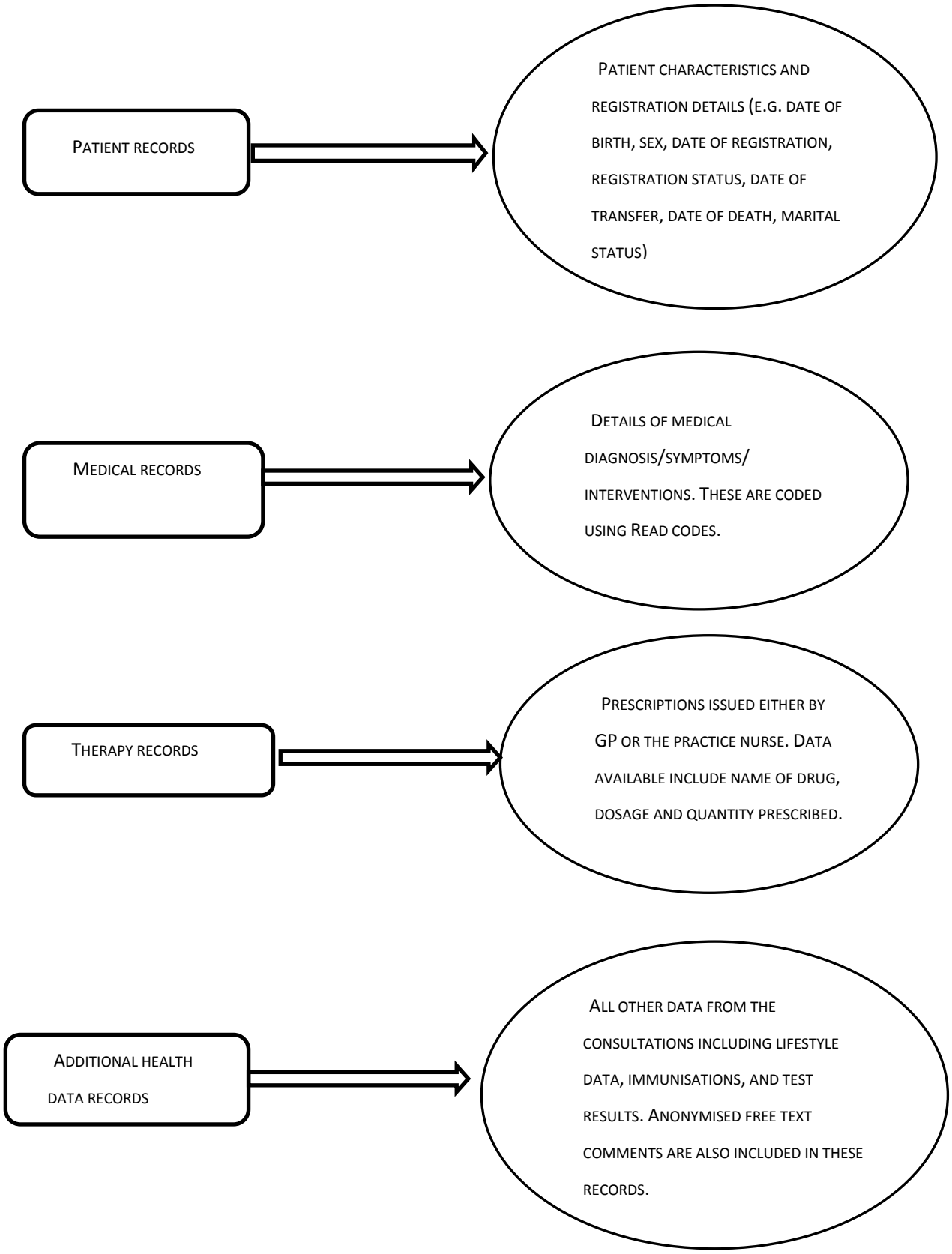


Figure 3-1 Data included within the THIN database

All practices contributing to THIN are checked to ensure that they meet set quality criteria namely the acceptable mortality reporting (AMR) and the acceptable computer usage (ACU) standards. AMR refers to the date after which the practice is deemed to have a mortality rate that is in line with the expected rate derived from the Office for National Statistics, after correcting for differences in demographic data [87]. ACU date, on the other hand, is the date after which the practice is confirmed to have contributed at least one medical record, one additional health record and two prescriptions per patient per year to the database [88].

3.4 AIMS AND OBJECTIVES

The aim of this analysis is to quantify the burden placed on NHS primary care in the UK and the WM due to paediatric allergy and related illnesses.

The objectives are

1. to estimate the GP diagnosed incidence, prevalence and diagnostic frequency rates amongst children aged 0-17 for the following conditions (see also Appendix Table 3.C):
    - allergic rhinoconjunctivitis
    - food allergy
    - drug allergy
    - asthma
    - eczema
    - urticaria
2. to compare the rates mentioned above for WM with those for the UK

3.5 METHODS

3.5.1 Study design

A retrospective analysis was carried out using data from practices contributing to the THIN database.

3.5.2 Inclusion criteria

Data from individual practices were considered only after the AMR and ACU dates. All children aged 0 to 17 years who registered for a minimum of one year between 1st January 2000 and 31st December 2015 in primary care practices contributing to the THIN database were included in the analysis. The children contributed to the dataset from the time of their registration with the practice until the earliest of their 18th birthday, transfer to another surgery, death or last data collection from the practice.

3.5.3 Outcomes of interest

The outcomes of interest were the annual incidence, prevalence and diagnosis frequency (as defined in section 3.5.3) of common allergic conditions in children encountered in clinical practice namely allergic rhinoconjuncitivitis, food allergy, drug allergy, urticaria, eczema and asthma between 2000 and 2015. These measures were used as indicators of disease burden and demand placed on primary care services. Comparisons were made between the rates for WM and those for the UK as a whole.

All entries into the THIN database are made by General Practitioners (GPs) and are driven by patient demand. The conditions that were considered in this analysis are described in the appendix (Appendix table 3.C). The Read codes used to identify these conditions are listed in Appendix table 3.D. Additional codes were used to identify prevalent conditions (also listed in Appendix table 3.D)

Children who were registered in with a GP practice within one month of birth were included in a "birth" cohort, whereas the rest (i.e., those who were registered at a surgery later in life) were included in a "transferred-in" cohort.

3.5.4 Ethical approval

The NHS South-East Research Ethics Committee approved the use of THIN for scientific research in 2003. Permission to access the THIN database for this study was obtained from a

Scientific Research Committee (SRC) which is linked to IMS Health (SRC approval number 13-021). The relevant permissions are shown in the Appendix (3.E).

3.6 ANALYSIS

Analysis was carried out using Stata 12® and Microsoft Excel 2010®. Using an open cohort of children aged between 0-17 years registered within the THIN practices, annual incidence and prevalence rates as well as age specific rates were determined within the chosen study period.

Rates and trends for specific allergies in the UK were compared with those for the WM.

3.6.1 Initial exploration of the database

The dataset was explored to understand the year on year variations in the numbers of registered patients in the UK and WM practices (Figure 3-2, Figure 3-3 and Appendix Table 3.F).

3.6.2 Outcome definitions

UK incidence rates (by calendar year as well as by age of child), period prevalence and diagnosis frequency of allergies were estimated for children aged 0-17 years between the years 2000-2015. Proportionate increase in these rates between the years 2000 and 2015 was also estimated, where appropriate.

Incidence

An incident case was defined as "the first ever presentation of an individual within the study with the condition of interest". In order to ensure that only new diagnoses were declared as incident in this study, we omitted transferred-in patients who were diagnosed within 6 months of their registration date with their primary care practitioner. This is in keeping with previously published literature using GP databases [89]. For eczema, a condition that is commonly diagnosed in early infancy [90], children who received the diagnosis within 3 months of their transfer to a new GP surgery were omitted from the analysis. All children in the birth cohort were included in the analysis irrespective of their time of diagnosis.

Incidence rate was defined as the number of incident cases for the given group divided by the total number of children in the group.

Prevalence

Prevalence is defined as the proportion of the population known to have a given condition. Annual prevalence rates were estimated as the total number of individuals with the condition divided by the total number of individuals in the dataset for a particular year.

Diagnosis frequency

The diagnosis frequency for a particular condition in this analysis refers to the likelihood of being diagnosed with the condition at any time since birth for the duration of inclusion within the dataset. Only children within the birth cohort were considered for this analysis.

Proportionate increase

This referred to the increase in the incidence, prevalence, consultation or prescription rate between the year 2000 and the year 2015 calculated as [(Rate(2015)-Rate (2000))/Rate(2000)]*100.

3.7 RESULTS

3.7.1 Initial exploration of the database

The uptake of Vision software amongst primary care practices varies from year to year. There was a rapid increase in uptake of the software by GP practices between 2000-2010, after which period the uptake reached a plateau followed by a slight decline. The dataset used for this study was obtained in May 2017. The entries in the dataset, therefore, ranged between August 1995 and May 2017. As shown in Figure 3-2 and Figure 3-3 , there were fewer than 100,000 entries for UK children and less than 10,000 for WM children before 2000. Also, the data for the year 2016 were not complete. Hence it was decided that the analysis would consider data between the years 2000-2015.

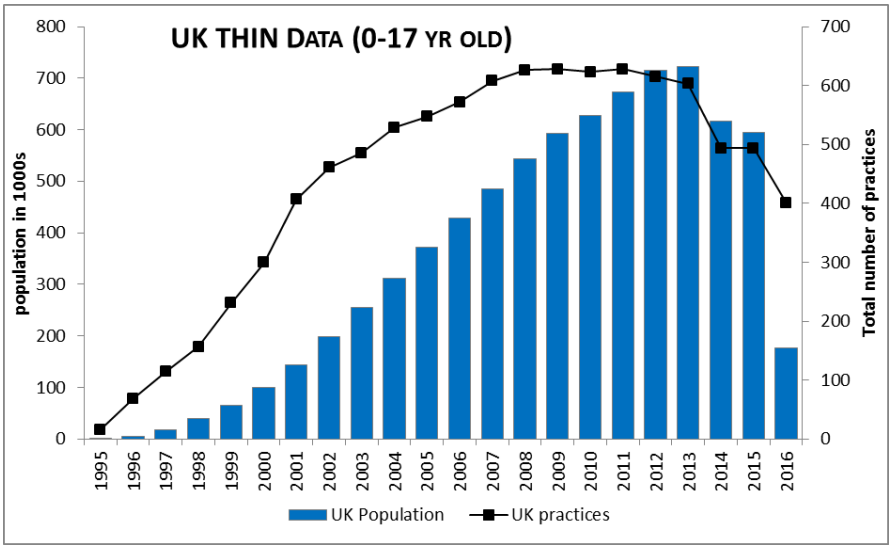


Figure 3-2: Total number of UK children and UK GP practices per year within the THIN dataset

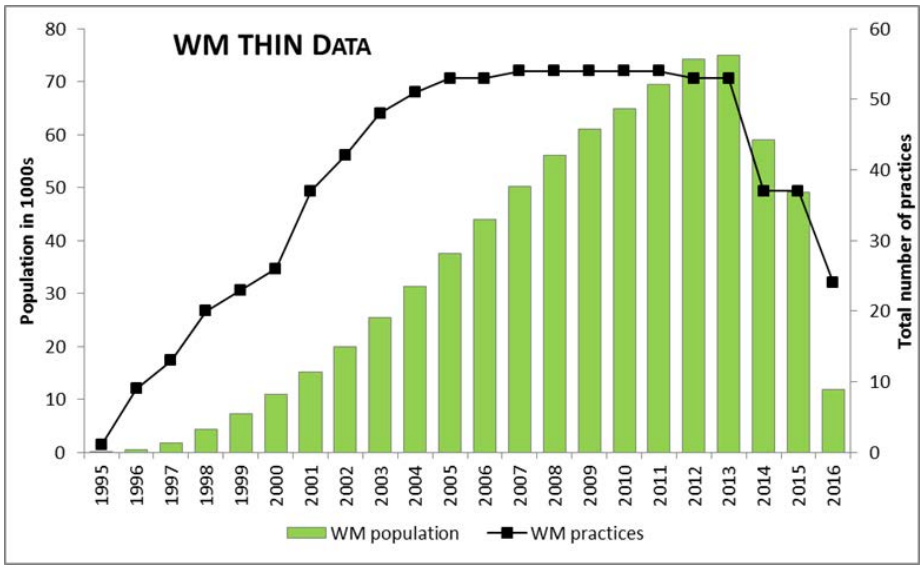


Figure 3-3: Total number of WM children and WM GP practices per year within the THIN dataset

Overall, more than 1.5 million children were included in the database during the study period (2000-2015) providing over 7.45 million person years of data for analysis. 557,902 children (37.1%) belonged to the birth cohort (i.e., they were entered into the database at birth) and 1315 (0.1%) children died during the study period. Most children in the database were from England (79.3%); Scotland, Wales and Northern Ireland accounted for 3.3%,10.2%

and 7.2% respectively. 48.8% (732,851) children were girls. 35.7% of all the registered children were diagnosed with an allergy or related condition (including allergic rhinoconjunctivitis, anaphylaxis, angioedema, urticaria, eczema, asthma, food allergy, drug allergy, insect venom allergy) during the study period. About 9.5% (n=143,348) of the children overall were from the WM, providing over 750,000 person years of data.

THIN is a dynamic database- i.e., the number of surgeries included in the database may increase or decrease over time as practices opt-in or opt-out of the database. Over the duration of the study (i.e., between the years 2000 and 2015), there have been some changes in the composition of the dataset. Whereas in the year 2000 over 2/3rds of the dataset comprised of children aged 5 or less, this reduced to about a third by the year 2015 (see Table 3-1). The proportion of children who were male remained fairly constant during the study period (Appendix Table 3.G)

Table 3-1: Proportion of children in specific age groups within the dataset between 2000-2015

Year	<=5yrs (%)	6-10yrs (%)	>10yrs (%)
2000	67.49	15.98	16.53
2001	66.01	16.62	17.37
2002	63.52	18.26	18.21
2003	60.75	20.41	18.84
2004	58.17	22.57	19.26
2005	55.80	24.36	19.83
2006	53.52	26.22	20.26
2007	51.38	27.51	21.10
2008	49.38	28.19	22.43
2009	47.54	28.64	23.82
2010	45.76	29.16	25.08
2011	44.51	29.17	26.32
2012	43.00	29.08	27.92
2013	41.03	29.29	29.67
2014	39.20	29.52	31.28
2015	36.73	30.01	33.27

3.7.2 Outcome1: Trends in the incidence of allergic disease in the UK

Annual incidence trends

The full dataset (i.e., including birth and transferred-in cohorts) was used for this analysis.

The overall incidence rates for general practitioner diagnosed allergic rhinoconjunctivitis (ARC) and food allergy (FA) amongst children aged 0-17 years in the UK have remained fairly constant between 2000-2015. The incidence rates of eczema, asthma and urticaria have decreased during this period (Figure 3-4 and Table 3-2).

The overall incidence rate for eczema amongst children is three times higher than that of allergic rhinoconjunctivitis and about 30 times higher than that of food allergy (see Figure 3-4).

The changes in overall incidence rates between 2000-2015 for most of the conditions considered in this analysis are summarised in Table 3-2.

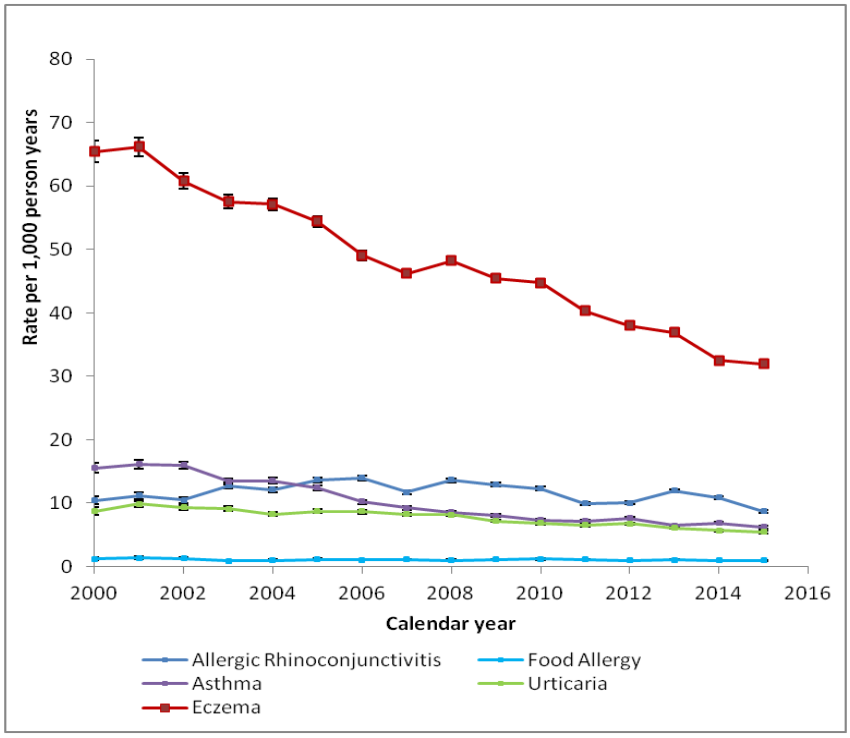


Figure 3-4: Incidence trends for eczema, allergic rhinoconjunctivitis, asthma, food allergy and urticaria amongst UK children(0-17 yrs). 95% CI are shown.

Table 3-2: Changes in incidence rate (per 1,000 person years) of allergies/ related conditions amongst UK children between the years 2000 and 2015.

Condition	2000 rate (95%CI)	2015 rate (95% CI)	% change (95% CI)
ARC*	10.4 (9.8-11.1)	8.6 (8.4-8.9)	-17% (-14.1to-19.7)
FA#	1.15 (0.96-1.4)	0.97 (0.9-1.1)	-15.6% (-6.6 to -23.7)
Eczema	65.4 (63.7-67.2)	31.9 (31.4-32.5)	-51.2% (-50.7 to -51.6)
Asthma	15.5 (14.8-16.4)	6.2 (6.0-6.4)	-60% (-59.2 to -60.7)
Urticaria	8.7 (8.1-9.3)	5.4 (5.2-5.6)	-37.9% (-35.6 to -39.6)

**Allergic Rhinoconjunctivitis #Food Allergy*

Incidence by age groups:

Since the change in the proportion of young children (Table 3-1) can impact on the overall incidence and prevalence rates for allergies, age specific incidence rates for these conditions were estimated. The results are presented in Figure 3-5 below.

The results show that whilst eczema, food allergy and asthma are more common in younger children, the incidence of allergic rhinitis is higher amongst older (aged >10 yrs) children. Whereas the incidence rates for food allergy appear to be stable across all age groups the rates for asthma have reduced, particularly in very young children (aged<=5yrs). This is also true for incidence rates of eczema. The incidence rate for ARC amongst children aged > 10yrs appears to have been decreasing over the last decade.

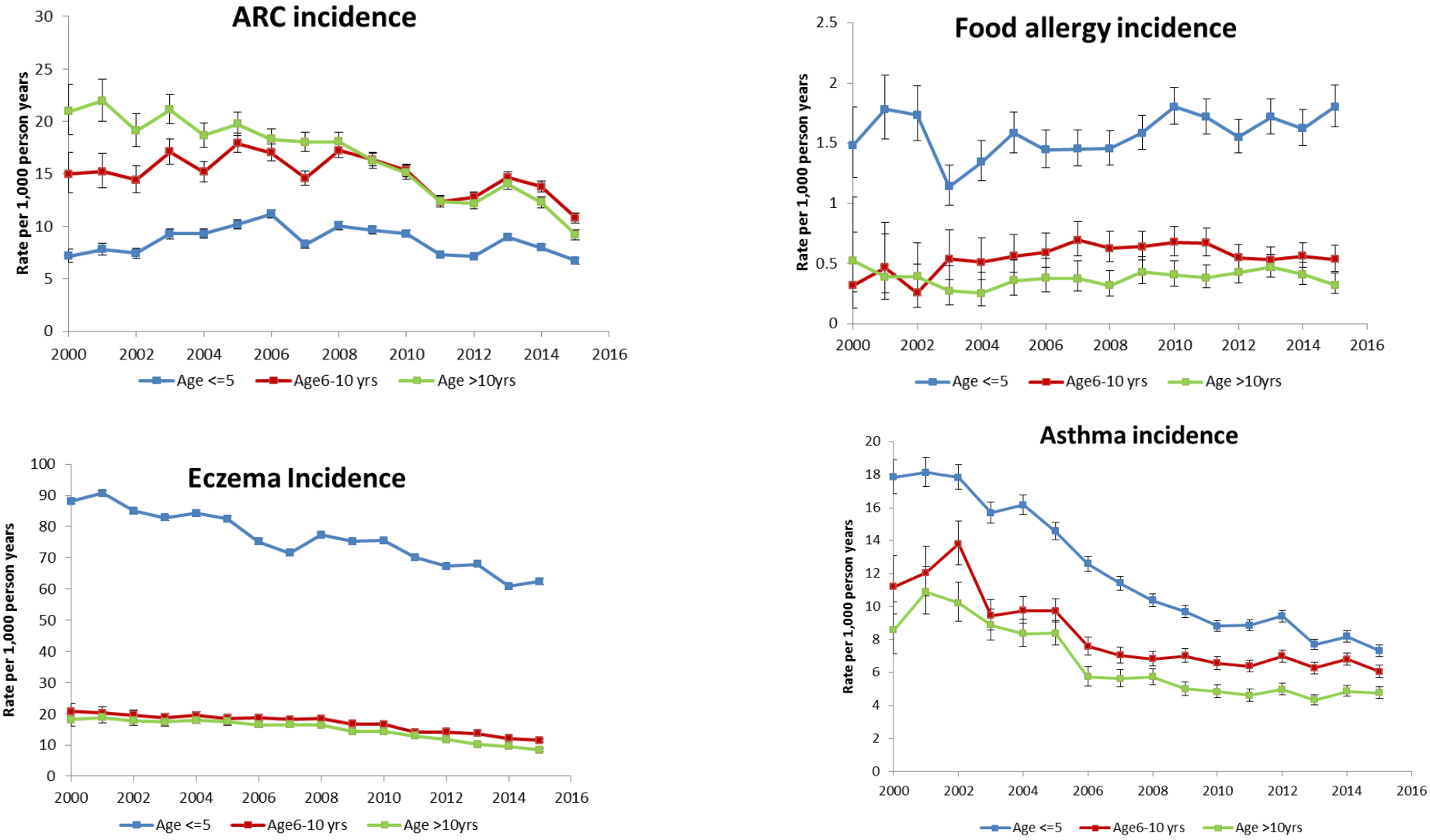


Figure 3-5: Incidence rates of allergic conditions amongst UK children as per age group. 95% confidence intervals are shown

Incidence by age

Physician diagnosed eczema is the most common allergy related condition in early childhood. childhood. The incidence is highest in the first 5 years of life, with most children diagnosed within the first year of birth (

Figure 3-6). Eczema incidence rate reduced considerably after the age of 5 years but was still higher than that of most conditions considered in this study.

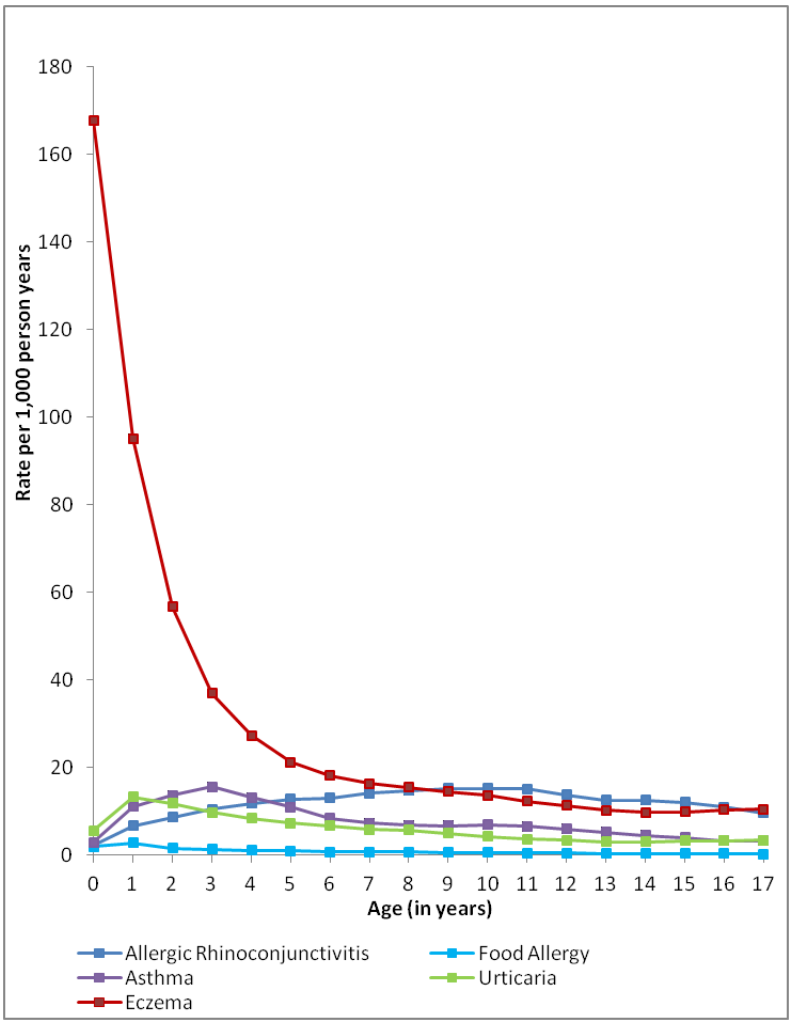


Figure 3-6:Incidence rate of allergies and related conditions amongst UK children by age (between years 2000-2015).95% confidence intervals are shown.

The diagnosis of ARC peaks at around the age of 9 years. Food allergy, on the other hand, is is most commonly diagnosed in children under the age of 2 years. Nevertheless, food allergy incidence rates are quite low relative to other conditions in children under the age of 5 years. Asthma and urticaria are also more commonly diagnosed for the first time in children aged 5

or under. The incidence rate of these conditions appears to plateau after the age of 10 years the UK (

Figure 3-6).

Boys under the age of 10 years are more likely than girls diagnosed with ARC and asthma in the UK. Food allergy diagnosis is also more common in boys up to the age of 6 years. There were no gender based differences in the incidence rates for eczema (see Figure 3-7).

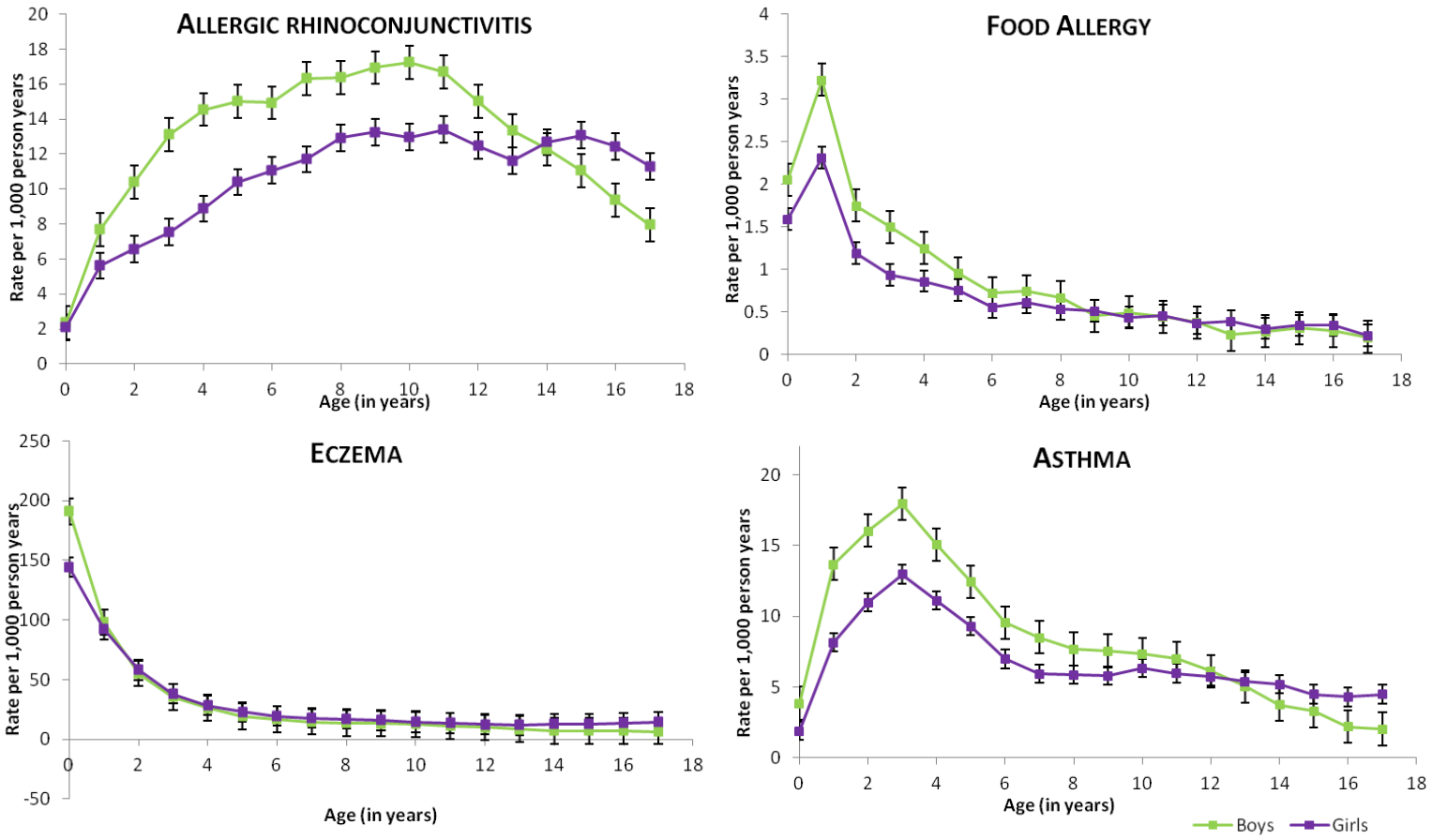


Figure 3-7: Gender differences in age related incidence of allergies and related conditions amongst UK children (2000-2015). 95% Confidence intervals are shown.

3.7.3 Outcome 2: Trends in prevalence of allergic disease in the UK

The full dataset (i.e., including birth and transferred-in cohorts) was used for this analysis.

Annual prevalence rate

The prevalence of most childhood allergic diseases in the UK has been steadily increasing over the period 2000-2015. The prevalence rate of ARC in the UK in 2000 was 35.1 per 1000 children compared with 91.3 per 1000 in 2015, an increase of 160%.

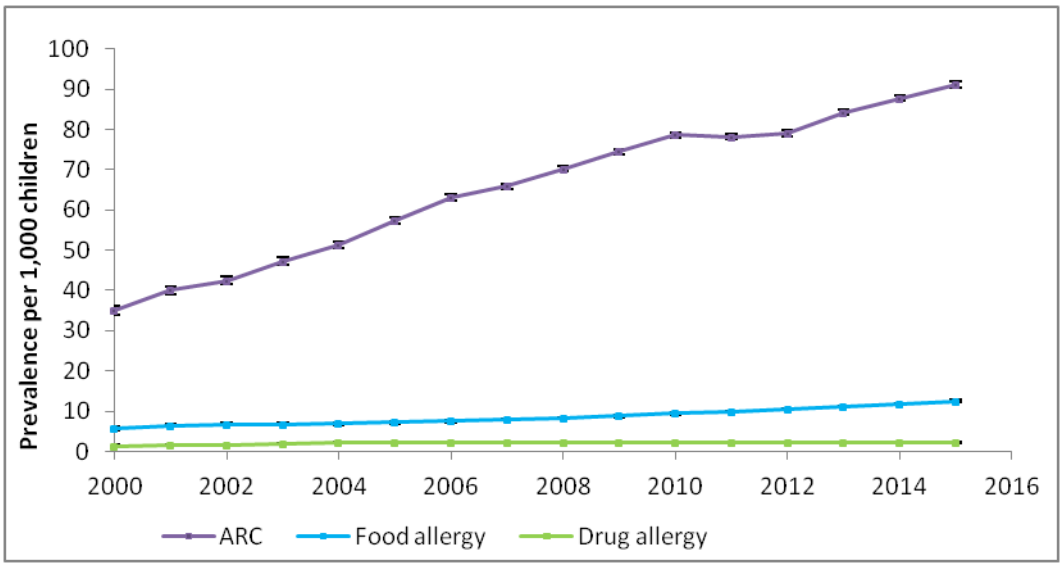


Figure 3-8: Prevalence trends between 2000-2015 of childhood allergies in the UK. 95% Confidence intervals are shown.

Prevalence of food allergy amongst children has showed a 120% increase in the UK between 2000-2015. During this period, egg allergy and nut allergy prevalence have increased by 81% and 275% respectively (see Table 3-3 and Figure 3-9).

Prevalence of eczema also increased during this period, although the prevalence of asthma has remained stable (Figure 3-10 and Table 3-3). Urticaria is an acute condition and was, therefore, not included in the prevalence estimates.

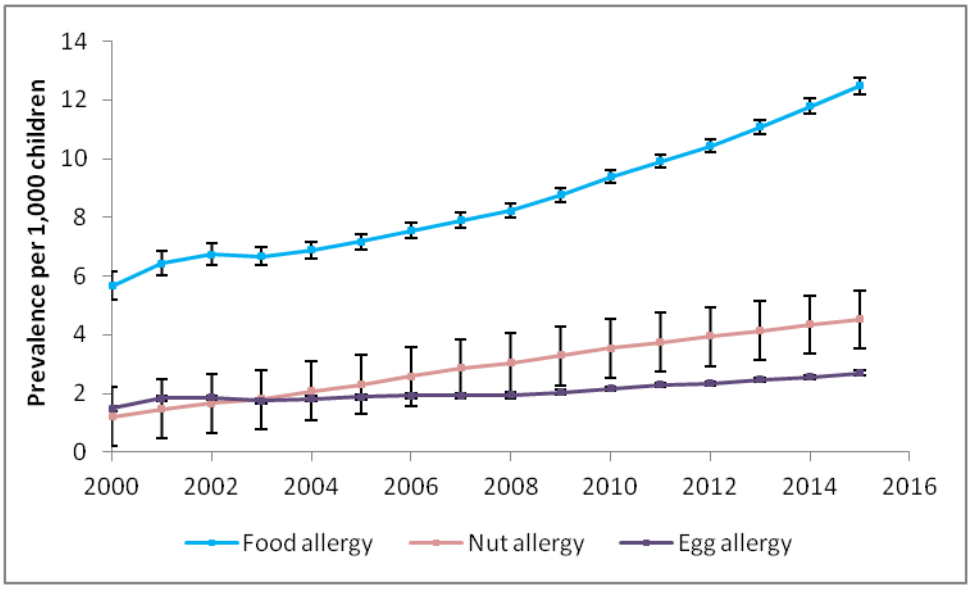


Figure 3-9:Annual prevalence trends for overall food allergy, nut and egg allergy amongst UK children. 95% confidence intervals are shown.

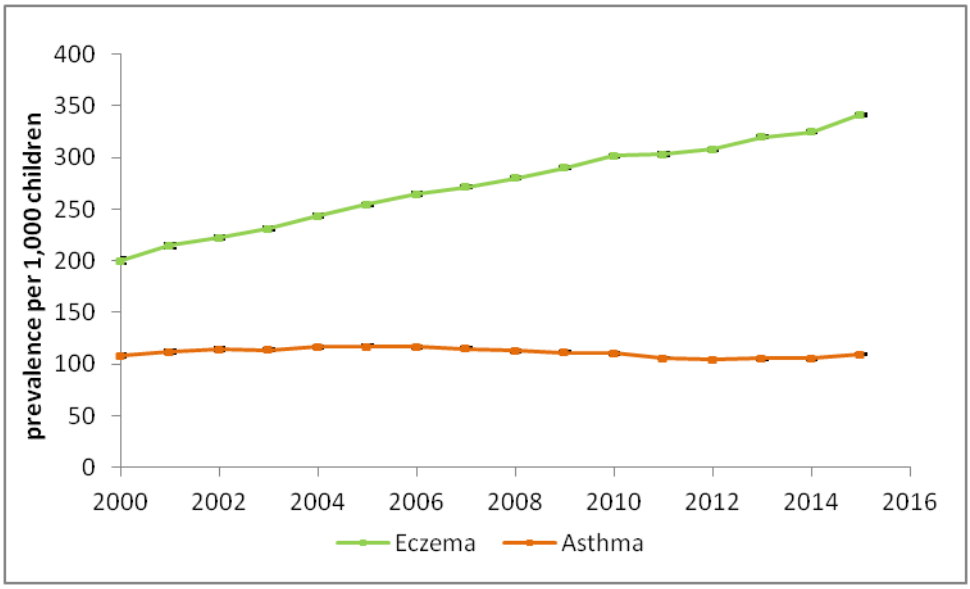


Figure 3-10 : Eczema and asthma annual prevalence trends amongst UK children. 95% confidence intervals are shown.

Most childhood allergies and related conditions have become more prevalent during the study period, with the exception of asthma. Overall, the prevalence of food and drug allergy are much lower than those of hay fever (allergic rhinoconjunctivitis), eczema and asthma (Table 3-3).

Table 3-3: Changes in UK childhood prevalence rates for allergies (per 1,000 children) between the years 2000-2015

Condition	2000 Prevalence (95% CI)	2015 Prevalence (95% CI)	% change
ARC	35.07 (33.9-36.3)	91.28 (90.5-92.1)	160.3 (153.9 - 160.3)
Food allergy	5.66 (5.2-6.2)	12.48 (12.2-12.8)	120.3 (107.6 - 133.9)
**Nut allergy	1.2 (1.0-1.4)	4.5 (4.4-4.7)	274.8 (225.5 - 331.6)
**Egg Allergy	1.5 (1.3-1.8)	2.7 (2.6-2.8)	81.32 (62.1 - 102.8)
Drug allergy	1.36 (1.2-1.6)	2.27 (2.2-2.4)	67.1 (48.9 - 87.5)
Eczema	200.03 (197.3-202.8)	341.4 (339.9-342.9)	70.7 (69.0 - 72.3)
Asthma	108.6 (106.6-110.7)	109.7 (108.9-110.5)	0.99 (-0.14 - 2.1)

**Children with nut and egg allergy are included in the food allergy estimates

Prevalence of complex allergies

The database was further interrogated to estimate proportion of children diagnosed with complex allergies, defined in this analysis as the diagnosis of two or more allergic diseases in a given child (Appendix table 3.C)

The number of children with complex allergies has been steadily increasing over the study period. The number of children diagnosed with both eczema and allergic rhinitis has increased by approximately 350% in the UK (see Figure 3-11 and Table 3-4). There has also been a steady increase in the number of children who have been diagnosed with eczema, asthma as well as allergic rhinitis during this period.

Table 3-4: Proportionate changes in the prevalence rates (per 1,000) of complex allergies amongst UK children between 2000-2015

Condition	2000 Prevalence (95%CI)	2015 Prevalence (95%CI)	% change
Eczema+ARC	10.02 (9.4-10.7)	45.51 (45.0-46.1)	354.1 (331.9 - 377.4)
Eczema+Food	3.05 (2.7-3.4)	8.23 (8.2-8.7)	177.1 (154.6 - 201.6)
Eczema+ARC+ Asthma	4.08 (3.7-4.5)	15.02 (14.7-15.3)	268.3 (241.1 - 297.6)
Eczema+Food+ Asthma	0.97 (0.8-1.2)	3.06 (2.9-3.2)	214.2 (169.6 - 266.1)
Eczema+ ARC+ Food+ Asthma	0.19 (2.7-3.4)	1.30 (1.2-1.4)	581.3 (368.0 - 885.9)

During the same period, the prevalence rate of a combination of eczema and food allergy has increased by over 175% (Figure 3-12 and Table 3-4). Similarly, the number of children with these two conditions as well as asthma also showed a 214% increase between the years 2000 and 2015.

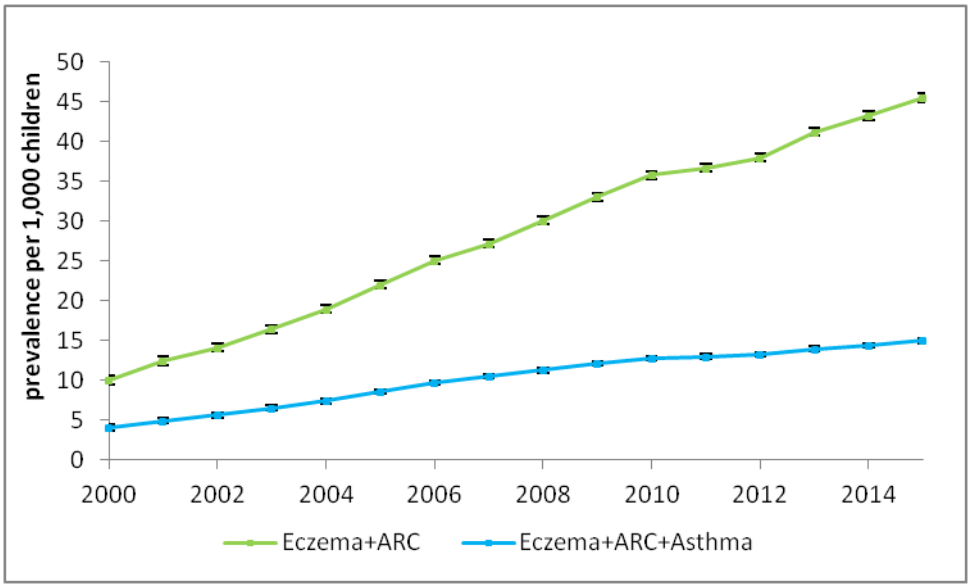


Figure 3-11:Trends in annual prevalence of allergic rhinoconjunctivitis in combination with other allergic conditions amongst UK children between 2000-2015 (95% confidence intervals shown for each estimate)

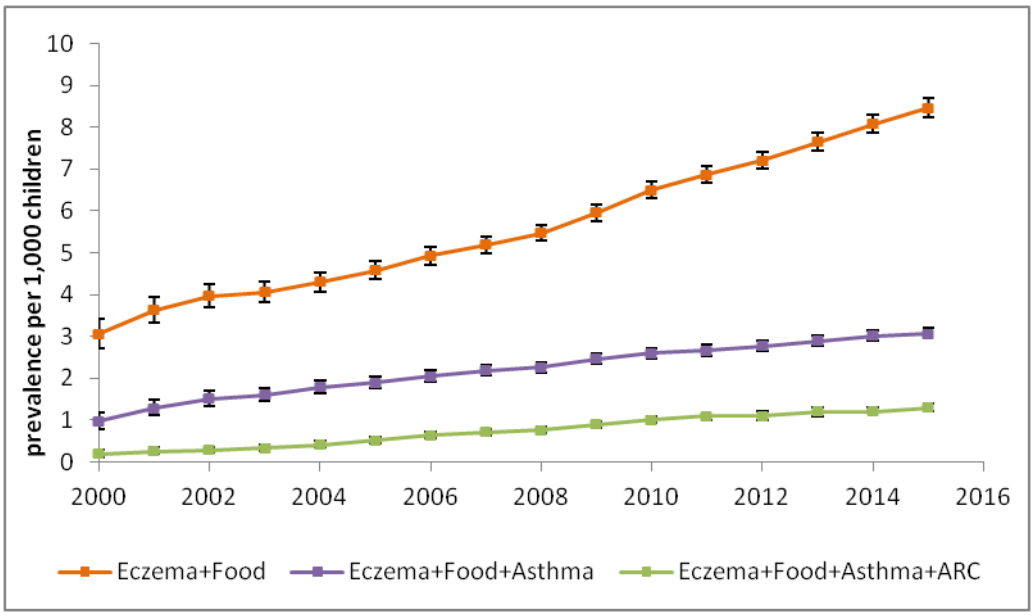


Figure 3-12:Trends in annual prevalence of food allergy in combination with other allergic conditions amongst UK children between 2000-2015 (95% confidence intervals shown for each estimate)

The most striking increase is in the proportion of children being diagnosed with all four conditions in childhood in the UK (i.e., eczema, food allergy, ARC and asthma)- over 580%. It should be noted, however, that a very small proportion of children are affected (Figure 3-12 and Table 3-4).

3.7.4 Outcome 3: Diagnosis frequency for allergic conditions amongst UK children

Only children who were in the 'birth' cohort of the database were included in this analysis.

About 1:4 UK children have been diagnosed with ARC by their GP by the age of 15yrs during the study period (Figure 3-13); One in 45 children have been diagnosed with food allergy by age 15, nearly 1 in 100 with nut allergy and 1 in 220 with egg allergy (see Figure 3-14 and Table 3-5). The burden of some of these conditions is evident at an earlier age, with 1 in 87 children already diagnosed with food allergy by the age of 5 years (see Figure 3-15 and Table 3-5).

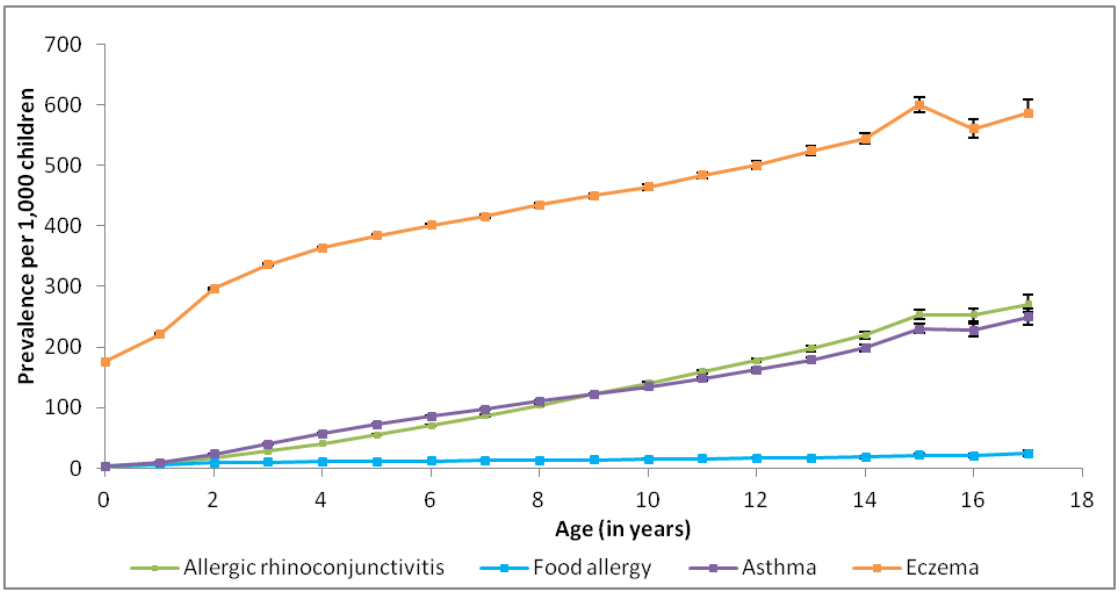


Figure 3-13: Proportion of UK children diagnosed by their GP at least once with an allergy at different age points. (Birth cohort only; 95% confidence intervals are shown).

Eczema, as previously noted, is very frequently encountered in UK primary care with nearly 1 in 3 children being diagnosed with the condition by their GP. Asthma and ARC are diagnosed later in life but by age 15, nearly one in four UK children within the THIN dataset has been diagnosed with each of these conditions by their GP (Figure 3-13 and Table 3-5).

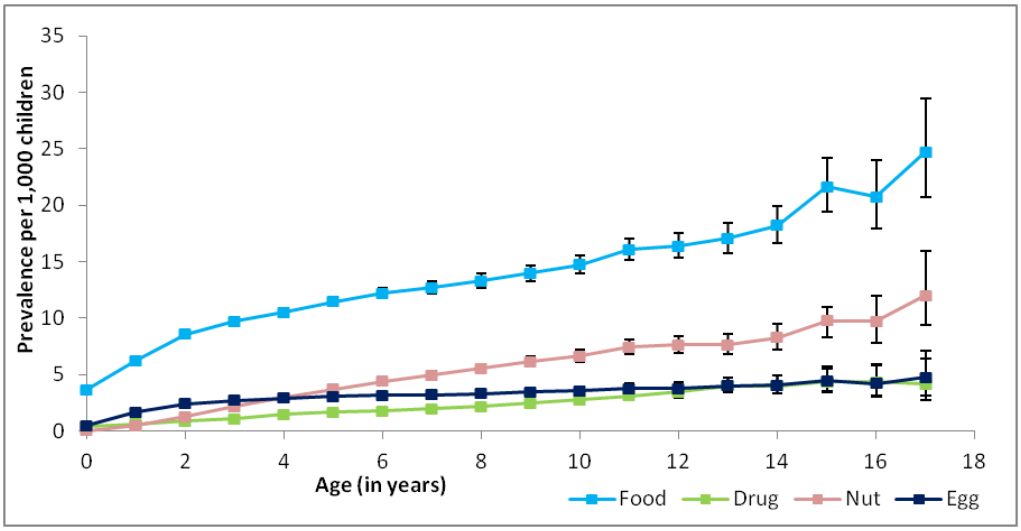


Figure 3-14: Proportion of UK children per 1,000 diagnosed with food, drug, nut or egg allergy at various age points. (Birth cohort only; 95% confidence intervals are shown for each estimate)

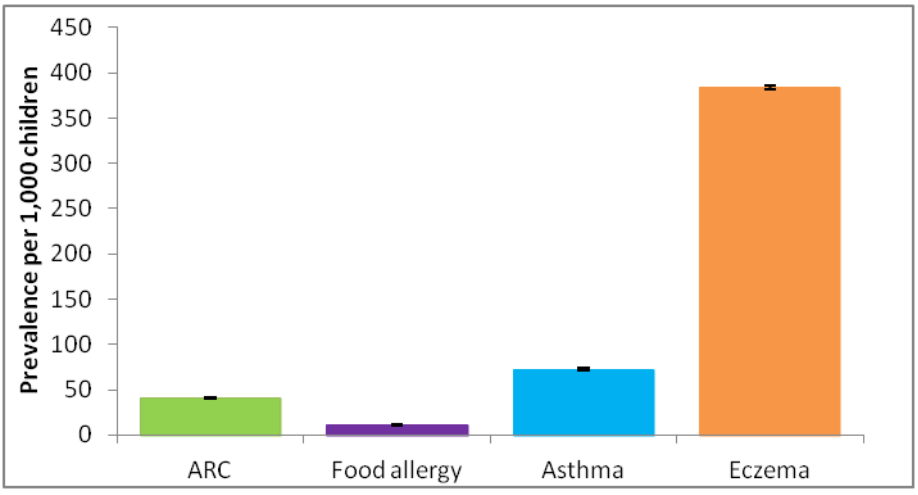


Figure 3-15: Proportion of UK children per 1,000 diagnosed with allergies by the age of 5 years (Birth cohort only; 95% CI shown in the figure)

Table 3-5: Increase in diagnosis frequency of allergies amongst UK children[$] (2000-2015)

Condition	Diagnosis frequency			
	Age 5 yrs*	Proportion[#]	Age 15 yrs*	Proportion[#]
ARC	55.6 (54.6-56.5)	1 in 18	253.8 (243.3-264.5)	1 in 4
Asthma	72.5 (71.4-73.6)	1 in 14	230.1(222.6-237.9)	1 in 4
Food allergy	11.5 (11.1-11.9)	1 in 87	21.7 (19.5-24.2)	1 in 45
**Nut allergy	3.7 (3.5-4.0)	1 in 270	9.8 (8.3-11)	1 in 102
**Egg Allergy	3.1 (2.9-3.3)	1 in 322	4.5 (3.5-5.7)	1 in 222
Drug allergy	1.7 (1.6-2.0)	1 in 588	4.4 (3.4-5.6)	1 in 227
Eczema	384.1 (381.7-386.6)	1 in 3	599.3 (587.1-611.8)	1 in 2
Urticaria	61.0 (60-62)	1 in 16	155.2 (146.5-163)	1 in 6

*$ Children from birth cohort only were included in this analysis*Number of children per 1000 with the condition; [#]values rounded to the nearest whole number*

3.8 ALLERGY BURDEN: UK VS WM

The burden of allergic conditions on primary care in the WM was explored vis-à-vis that of the UK. The annual prevalence of allergic rhinoconjunctivitis (ARC) was consistently higher in the WM region compared with that of the UK, whereas there was no appreciable difference in the prevalence rates for food allergy, asthma and eczema (Figure 3-16).

The rate of complex allergies was found to be higher for conditions including ARC in the WM (Figure 3-17).

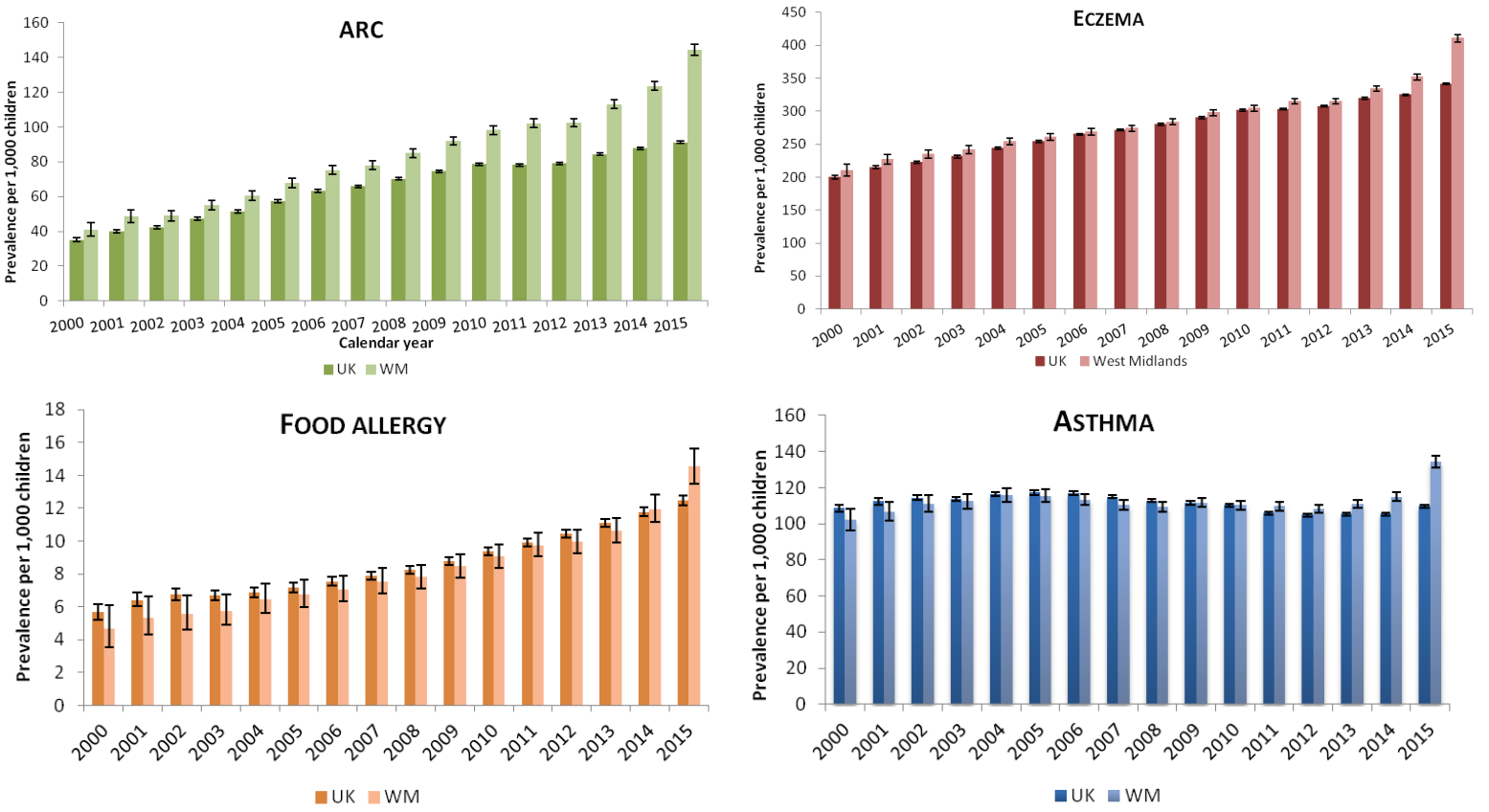


Figure 3-16: A comparison of prevalence rates per 1,000 children of allergic rhinoconjunctivitis (ARC), eczema, food allergy and asthma for children aged 0-17yrs in the whole of the UK compared with those from WM.. 95% confidence intervals are shown.

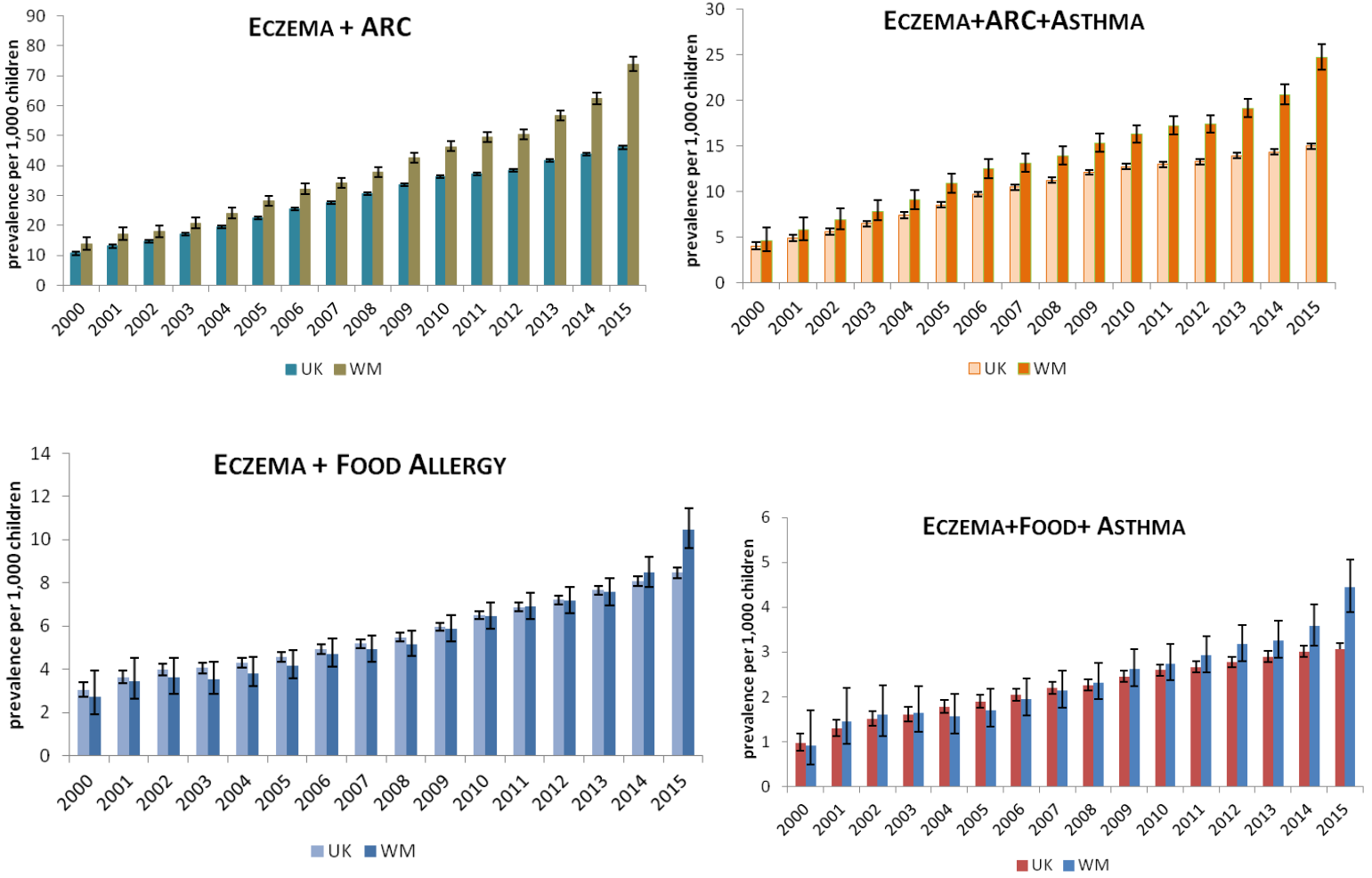


Figure 3-17: A comparison of the prevalence rate per 1,000 children of GP diagnosed complex allergies in UK versus WM.. 95% confidence intervals are shown.

3.9 DISCUSSION

Incidence rates

The incidence rates of food allergy, allergic rhino conjunctivitis (ARC) and urticaria amongst children have remained fairly stable in the UK during the study period (2000-2015). During this time, the overall incidence of asthma and eczema have decreased steadily. However, the incidence rates of eczema are substantially higher in very young children (aged ≤ 5yr). Eczema, asthma, urticaria and food allergy are all more commonly diagnosed in children under the age of 5 years. By contrast, ARC is relatively more commonly diagnosed for the first time in older children. Boys, especially those under the age of 6 years, are more commonly diagnosed with food allergies, ARC and asthma compared with girls.

Prevalence rates

The prevalence rates for all the allergic conditions investigated (except asthma) have increased in the UK over the study period. ARC prevalence rates have more than doubled; prevalence rates for eczema were higher than that of any other condition investigated in this analysis. Despite the fact that overall incidence of eczema fell within the dataset, the high incidence in the very young children (relative to children aged over 5 years - see Fig 3.5) meant that the total number of children within the dataset with this condition has been increasing over the study period. Consequently, between 2000 and 2015, there has been more than a 50% increase in eczema prevalence amongst children in the UK. About one in 45 children in our dataset were diagnosed with a food allergy and one in 100 with a nut allergy by the age of 15. About 1 in 3 children were diagnosed with eczema by the age of 5 years and over half of all children by the age of 15.

The International Study of Asthma and Allergies in Childhood (ISAAC), a large multi-centre study estimating the prevalence of self- reported allergic conditions, found that whilst eczema and asthma prevalence had levelled off or decreased in areas with previous high prevalence (such as the UK) [91], the prevalence of allergic rhinitis – especially in younger children- has increased in most countries [68]. Estimates vary significantly based on the

method used (e.g. self-report versus diagnosed by a doctor), definition of allergy itself (blood test positivity versus self-reporting of symptoms by patient versus challenge test in a clinic) , age groups studied, or, in the case of retrospective cohort studies (similar to those presented in this thesis)- the dataset used [92].

The reasons for the high prevalence of allergies in the Western world are unclear. The 'hygiene hypothesis' which postulates that reduced exposure to dirt increases predisposition to allergic disease is currently the most accepted theory [93], but this does not offer a complete explanation [94]. It is noteworthy that the prevalence rates of allergy in some low and middle income countries have increased significantly within the seven years between ISAAC study phase 1 and 3 [68] suggesting that allergy could, perhaps, become a significant problem in the developing world in the future.

Prevalence of GP reported food allergies has increased substantially amongst children during the study period. However, while there is broad agreement that food allergies are increasing in prevalence, the actual estimates are much debated [95]. This trend has been reported globally [96], although the quality of epidemiological data from different countries is variable. There was a marked increase in nut allergy prevalence at 275% in our cohort during the study period. The increase is in keeping with published literature from the UK and worldwide [97-99]. The reasons for such an increase are not entirely clear. Coding practices and bias due to practices included in the dataset may play a role, but published literature suggests that this may be a real trend. Epidemiological studies suggest that family history of allergy, association with other atopic diseases, route of allergen exposure (e.g. through skin), timing of exposure to the allergenic food and other dietary factors (such as reduced omega 3 fatty acids) may all contribute to the risk of developing food allergy [100]. With regards to peanut allergy, more recent publications suggest that early weaning (at 4 months of age) with exposure to peanut may be protective [101]. However, this is at odds with the Department of Health's previous recommendation (which was rescinded in 2008) advising avoidance of peanuts during pregnancy and the first 3 years of life in atopic children [102]. It is not clear

whether the previous guidance has contributed to the increase in nut allergy prevalence during the last decade (2000-2010). There has, however, been no abatement in the upward trend of in prevalence even after the withdrawal of the guidance.

A previous publication has reported an increase in the incidence of GP diagnosed ARC in the UK [103]. Although this study did not report the trends for children in particular, other studies have suggested that allergic rhinitis has been increasing over time with each birth cohort [104]. Food allergy is more commonly diagnosed in children aged 5 years or less, whereas ARC is more commonly diagnosed in teenagers. Boys in our dataset appear to have a higher incidence of food allergy, ARC, asthma compared with girls until age 6yrs- this has previously been reported in the literature [105, 106]. The reasons for such discrepancy are not fully understood. Hormonal differences have been cited as a possible explanation[105], although this has not been proven.

Proportionate changes in allergy prevalence

The proportionate increase in asthma prevalence was lower compared with that of other conditions explored in this analysis. Previous studies and reviews have reported the flattening in asthma prevalence rates since 2000 [107]. One study reporting data from the General Practice Research Database (GPRD) showed an increase in asthma prevalence during the 1990s [108]. A more recently published systematic review suggests that the prevalence worldwide is perhaps increasing [109]. However, the review included data from self-reported and physician diagnosed studies and did not clarify the age groups of the population studied.

Complex allergies

The number of children in our cohort with multiple allergies has increased considerably between 2000 and 2015. A previous publication using the GPRD database demonstrated that children diagnosed with either eczema, asthma or allergic rhinitis were at higher risk of developing other allergic conditions [110]. While this may be a global trend [111], the actual extent of the problem has not been previously described. An Irish study used the standardized ISAAC questionnaire to conclude that the co-existence of atopic conditions amongst children

aged 6-7 years had increased between 2002-2007 [112]. The increase in complex allergies has implications for the clinical services for allergy given that these children are most likely to need specialist input for optimal management. However, as discussed in the previous chapter, there are significant issues with specialist availability in allergy [6, 7]. In addition, poor referral practices often result in delays in assessment of these children [13].There is a need to streamline care pathways in order to ensure that these children are looked after well in the NHS.

Burden in the WM

The prevalence rates of allergic disease in the WM are broadly similar to those within the UK, except for ARC which appears more common in the WM. This is an interesting finding, perhaps related to the relatively longer pollen seasons coupled with higher pollen counts noted in the central parts of England [113]. The rates of complex allergies in the WM are also higher than those of the UK as a whole. This has implications for allergy services, especially given that the paediatric allergy specialist availability in the region is known to be poor [114].

3.9.1 Strengths and limitations of this study

This study is the first, to our knowledge, to estimate allergy disease burden for a UK region. A major strength is the use of a large, representative national primary care database (THIN) which includes data from across the UK. The dataset provided longitudinal data on over 1.5 million children spanning over a decade and a half, allowing estimations with high statistical power. THIN provides diagnoses documented by a qualified clinician and could be considered to provide a more credible estimate than that provided by self- reported allergies. However, many mild allergies are managed by patients (and parents) at home using over the counter medication without ever consulting general practitioners. Thus, the estimates in this study may not reflect the burden of disease in the community. Moreover, as with any health database, there could be issues with accuracy of coding and missing data. In addition, THIN is a dynamic database and various GP practices may have joined or left the dataset during the study period. This may have affected the estimates provided. In addition, the GP surgeries that

opt to join the THIN data group may be more pro-active and outcome oriented, leading to a systematic bias in the data obtained. It should be noted, however, that data from THIN has been shown consistently to be of high quality and completeness as well as generalisable to the UK population [82, 115-117]. There are, however, no published data discussing the accuracy or generalisability of THIN estimates for different regions of the UK.

We included all children who were diagnosed with allergic disease in our analysis without reference to prescriptions or consultations. This may have provided an overestimate of allergies, although it is important to remember that many allergic conditions (including allergic rhinoconjunctivitis, eczema, urticaria) are frequently managed using over the counter preparations and no prescriptions are often necessary for drug allergies and mild to moderate food allergies. In addition, it can be argued that disease diagnosis is an unreliable marker of disease burden compared with disease severity (which was not estimated in this analysis). Estimating disease severity for most allergies using the THIN database, however, can be challenging since there are no reliable Read codes that describe disease severity and many of the drugs used in managing these conditions can be obtained over the counter.

Strengths and limitations in relation to published data

A previous study estimated UK allergy incidence and prevalence rates for eczema, asthma and allergic rhinitis using primary care databases (particularly the GPRD) [22] - results from the current study broadly concur with these published estimates.

The Europrevall study carried out gold standard double blind, placebo controlled challenge tests on all children suspected to have food allergies [81]. Hens egg allergy prevalence in this cohort was estimated as 2.18% in the UK (95% CI 1.27–3.47) [118], about 10 fold higher than the estimations from our analysis. The UK recruiting centre for this study was Southampton- it is unclear whether the differences in estimates may be related to geography (although this is highly unlikely given the scale of difference) or whether there is a significant under-diagnosis of food allergies in UK primary care.

3.10 CONCLUSIONS

The incidence of primary care physician diagnosed allergic rhinoconjunctivitis, food and drug allergy, urticaria amongst UK children has remained stable over the study period (2000-2015). Asthma and eczema incidence has been falling. The prevalence of all the conditions (except asthma) amongst UK children explored in this study, including complex allergies, has increased during the study period. The allergy prevalence rates are similar in the WM except for allergic rhinoconjunctivitis and complex allergies, which are more prevalent in this region. The data suggest that there may be some differences in the regional needs for secondary care services which require further exploration. Estimates of demand can be important when planning allergy services for children.

While THIN analysis has shown that the prevalence of GP diagnosed allergies amongst children is increasing, it is important to look at the number of children being admitted into hospitals with these conditions in order to obtain a more complete picture of allergy related demand on the NHS. Analysis of a secondary care NHS database (HES) is discussed in the next chapter.

4 Analysis of Healthcare Databases- The Hospital Episodes Statistics Database

The previous chapter was focused on the epidemiology of paediatric allergy and related conditions from the UK primary care perspective. In order to fully understand the pathways involved in allergy service provision, it is important to understand the nature and frequency of allergy and related conditions presenting to secondary care. The current chapter will focus on the burden posed by paediatric allergy on NHS secondary care in England and the WM using data from the Hospital Episodes Statistics database (HES).

4.1 BACKGROUND

4.1.1 Admissions related to allergies

In the previous chapter the annual trends in incidence and prevalence rates of GP diagnosed childhood allergies in the UK were discussed and these were compared with the rates for the WM. In this chapter, the burden placed on secondary care due to paediatric allergy and related conditions will be discussed.

For this analysis, the Hospital Episodes Statistics Database (HES) was used. HES is a secondary care dataset containing details of all admissions into NHS hospitals in England. This dataset does not record Accident and Emergency attendances, nor does it provide details regarding outpatient appointments into NHS hospitals. On an average, 125 million records per year are included in the database. In addition to NHS admissions, it provides information regarding admission of private patients treated in NHS hospitals, patients resident outside of England (whose care is delivered within English NHS hospitals) and care delivered by treatment centres (including those in the independent sector) funded by the NHS in England. Spells where individuals living in England seek treatment by the NHS in the devolved nations are not included in the database [119].

As with the previous chapter, the results from England will first be discussed (since HES data do not include episodes from Wales, Scotland or Northern Ireland) and comparisons will then be made with data from the WM.

4.1.2 About HES

The HES database was initiated in 1989-90 and, in parallel with changes to the NHS structure, has since undergone many changes in terms of data collection, coding and responsible agency. It is now run by the Health and Social Care Information Centre (HSCIC) and the National programme for IT under the Secondary Uses Service (SUS). It includes patient admissions care data from 1989 onwards, outpatient attendance data from 2003 onwards and A&E data from 2007 onwards. HES is updated every month [119]. In order that

data remain anonymous, all patient identifiers are removed and, in the case of very rare diseases, statistics are suppressed so that individuals cannot be identified using the database.

HES data are different from Payment by Results (PbR) data which are submitted by NHS Trusts every month to declare their clinical activity for the purposes of financial compensation [119]. Unlike PbR, HES data are not updated once released.

4.1.3 Data captured within HES

Each HES record contains a wide range of information about an individual patient admitted to an NHS hospital, including:

- clinical information about diagnoses and operations (except for outpatient attendances where no such clinical information is available). Up to 20 diagnoses and 20 procedures can be recorded per admission. These are coded as per the ICD-10 (International coding of diseases) and the OPCS classification of interventions and procedures (OPCS4) codes.
- information about the patient- such as age group, gender and ethnicity
- administrative information, such as time waited, and dates and methods of admission and discharge including whether or not the admission was elective (planned) or an emergency.
- geographical information such as where patients are treated and the area where they live, electoral ward of residence, Clinical Commissioning Group (CCG) region etc.
- Socioeconomic data are estimated based on English indices of multiple deprivation (IMD 2010) which are published for small geographical areas. This is a composite measure that uses 38 indicators of deprivation which are grouped into 7 domains including income, employment, health and disability, education, skills and training, barriers to housing and other services, crime, living environment. Scores from each domain are weighed differently to determine the deprivation ranking of the given geographical area [120]. The higher the overall IMD rank, the lower the deprivation.

4.1.4 Permissions to access the database

In order to access the HES database, an application was made to the Data Access Advisory Group and the Confidentiality Advisory Group by the Institute of Applied Health Research within the University of Birmingham. Approval was provided for a range of research projects including this study. Data was made available for the period 2007-2015.

4.2 HES ALLERGY DATA

4.2.1 Admissions due to allergies

Allergy related admissions into NHS Trusts in England may be elective or emergencies.

Allergy related emergencies

Emergency admissions for allergy commonly include those due to anaphylaxis, angioedema and urticaria.

Anaphylaxis

Anaphylaxis is "a serious allergic reaction that is rapid in onset and may cause death" [121]. It has previously been reported that the incidence of anaphylaxis in the UK is increasing, although there is considerable discrepancy in the proposed incidence rates for the condition which have been reported to vary between 5 to 40 per 100,000 population [75, 77, 122, 123]. The lifetime prevalence estimates worldwide vary between 0.05 and 2% [124, 125].

Angioedema

Angioedema refers to non-itchy, painless swellings of the skin and mucous membranes which may nor may not be related to an underlying allergy [126]. The condition is normally not serious but can be rarely life-threatening, especially when the swelling affects the tongue or the inside of the throat. Patients may attend A&E department when symptoms are distressing or serious.

Urticaria

Urticaria refers to a group of skin disorders characterised by the development of localised, itchy, transient wheals [127]. This is a common skin disorder that can lead to a

significant impairment in an individual's quality of life. The condition may or may not be related to an underlying allergy. Whilst most individuals with urticaria are managed by GPs or specialists in the outpatient clinics, some may have severe symptoms and discomfort prompting a visit to the emergency department.

Elective admissions for allergies

Immunotherapy (Desensitisation treatment)

Some children with allergic rhinitis (hay fever/ house dust mite allergy and related conditions) are electively admitted to hospital for administration of desensitisation treatment [128] (also known as specific allergen immunotherapy or SIT) as day case admissions given the prolonged duration of observation required after every dose (up to 1 hour) and the possibility of anaphylaxis during treatment. Allergen SIT in the UK can only be administered in specialist centres- primary care practitioners are not licensed to provide this therapy. It can be given either subcutaneously (i.e., via injections- SCIT therapy) or through tablets under the tongue (sublingual or SLIT therapy).

Elective day case admissions are usually planned for injection SIT whereas tablet SIT can be delivered mostly at home although a couple of elective admissions will be offered to patients (usually for treatment initiation or for monitoring those experiencing side-effects).

Challenge tests

In children with suspected allergies (usually food allergies), challenge tests with the implicated allergen are sometimes planned to either confirm or rule out allergy. These are done under supervision of experienced clinical staff and are marked as a day-case elective admission.

4.3 AIM AND OBJECTIVES

The aim of this study was to estimate the number of admissions into the NHS hospitals in England due to conditions related to paediatric allergy between 2008 to 2014.

The objectives were:

1. To estimate the admission rates for children into English hospitals for the following conditions:
   i. Allergy emergency versus elective admissions
   ii. Emergency admissions:
      - Anaphylaxis
      - Urticaria
      - Angioedema
2. To compare the admission rates between English and WM children for
   i. Anaphylaxis
   ii. Urticaria
   iii. Angioedema
3. To compare admissions for allergen specific immunotherapy for English and WM children

4.4 METHODS

4.4.1 Data collection

Diagnosis and symptom related information in HES are coded using the ICD-10 clinical coding system, whereas clinical procedures are coded using the OPCS4 system [119]. The conditions of interest and the corresponding codes used in this analysis were drawn from the published literature [122, 129], including a special publication from the HSCIC with a focus on allergies [128]. The list of conditions of interest to this study and the relevant ICD-10 codes are shown in Appendix Table 4.A

In addition to the diagnostic codes, other data which were felt to be relevant including age, sex, ethnicity, region where treatment was delivered, IMD data (see section 4.1.3), dates of admission and discharge etc. were extracted for each allergy related admission [130]. The

region in which the patient resided at the time of the admission was derived from the GOR (Government Office region of Residence) code which is routinely collected within HES [131].

The relevant population data (for England and the WM) were derived from the ONS mid-year population statistics [132].

Data were extracted by an experienced analyst (Mr Gavin Rudge, University of Birmingham) on the 31st of August 2016 based on the requirements specified by the researcher (LD).

4.5 ANALYSIS

The data were analysed using Stata® 13 and graphs were created using Stata and Excel® 2010. Admissions/ treatments for anaphylaxis, as well as those for allergic rhinitis were focused upon. Admissions for asthma in children were not considered in this analysis.

The University had access to HES data for the years 2007-2015. Since the HES data span the financial year (i.e. 1st April to 31st March of the following year), the complete annual estimates (1st January- 31st December) were available only for the years 2008-2014. The data shown in this chapter, therefore, are estimates for 2008-14. In order to estimate age and gender-specific admission rates for England (and WM) for these conditions, the relevant mid-year population estimates for children using the data published by the Office of National Statistics (ONS) were used [132].

4.5.1 Assumptions

The following assumptions were made during this analysis:

i. The coding data and all the other entries made into the dataset were considered to be accurate
ii. Anaphylaxis coded within any of the 20 available diagnostic code options per admission was considered significant and was included in the analysis
iii. Urticaria and angioedema were assumed to cause the admission if they were included within the first 3 diagnostic codes only.

iv. Individuals presenting with anaphylaxis may also have urticaria and angioedema. To prevent double-counting, those individuals listed as being admitted for anaphylaxis were removed from the urticaria and angioedema admission statistics.

v. All treatment codes (up to 20 per admission) were considered in estimating the admissions for desensitization (i.e., SIT)

4.5.2 Admission rates

Age and sex specific admission rates for various allergies and related conditions were estimated using population estimates provided by the ONS [132].

4.6 RESULTS

There were 87,048 finished admission episodes of hospital admissions for children with allergies (identified using ICD-10 and OPSC4 codes- see Appendix Table 4.A) between the years 2008 and 2014. 44.9% of these were recorded as elective admissions and 54.6% were emergency admissions (0.5% were not specified as either). 59.5% were boys; 65.9% were identified as white; 3.7% were of mixed ethnic origin; 13% were Asian, 5.5% were of black origin and 2.8% were labelled 'other' whereas ethnicity data were unavailable for 9.2% of the children. 31.3% of the children were aged 5 years or less.

Over 90% of the children had no more than 4 diagnostic codes and 2 procedure codes entered per admission. Breakdown of the admission data by geographical regions is shown in Appendix Table 4.B. The data from West Midlands (WM) accounted for 8.3%, the North West of England accounted for over a quarter and London for a fifth of all allergy related admissions for English children between 2008 and 2014. The proportion of children in England and the WM in the age groups 0-5 yrs, 6-10 yrs and 11-17 years has remained fairly constant during the study period (see appendix 4.C)

4.6.1 Allergy related admission rates

Emergency versus Elective admissions

There has been a steady increase in the number of English children admitted into hospital either electively or as an emergency with any allergy related diagnostic code as shown in Figure 4-1 (See also Table 4-1), with a 75% increase between 2008 and 2014.

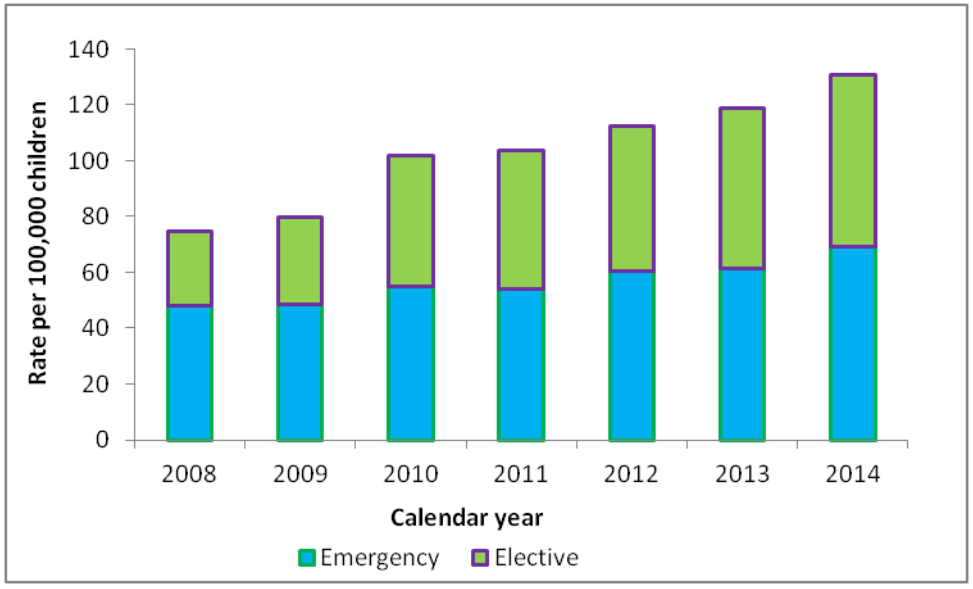


Figure 4-1: Allergy admission rates for children in English NHS (Elective versus Emergency)

Admissions due to Anaphylaxis

The rate of admission of children into hospitals in England with anaphylaxis is shown below (Figure 4-2). Boys have had higher admissions rates for anaphylaxis between 2008 and 2014 compared with girls.

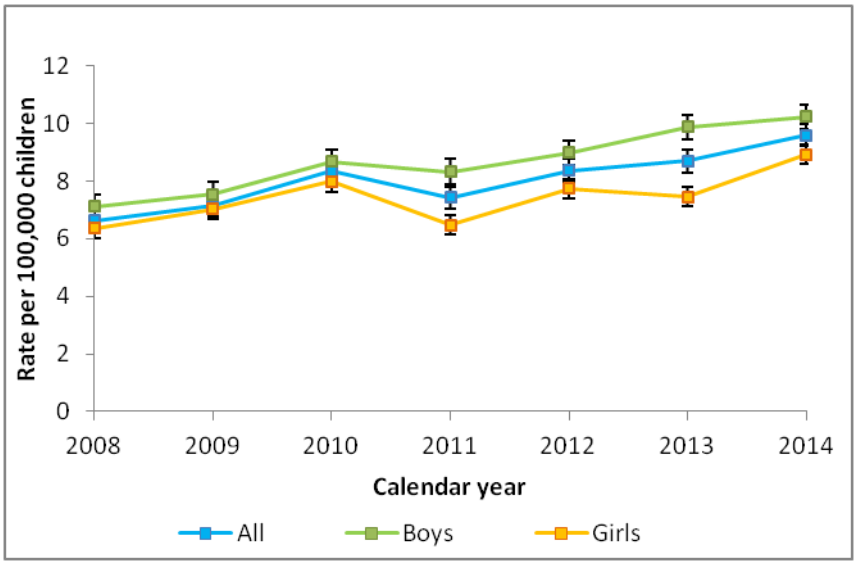
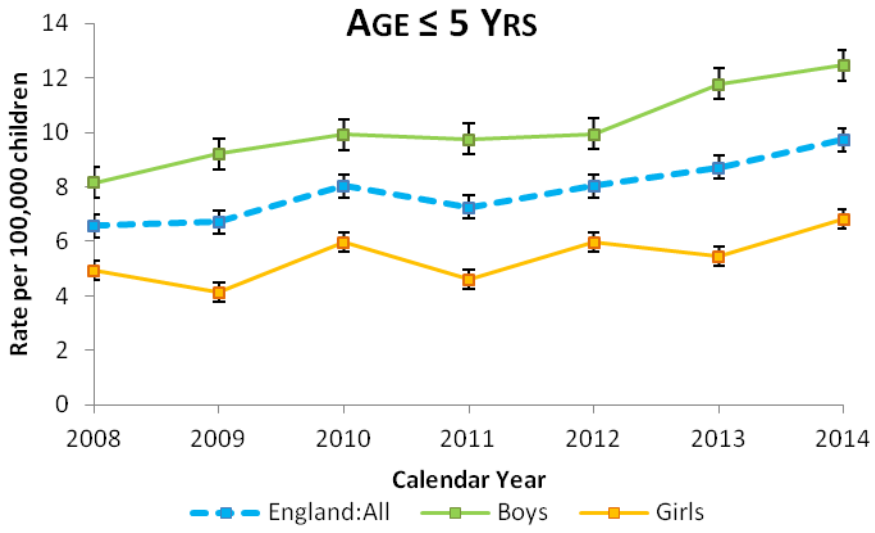


Figure 4-2: Anaphylaxis admission rates with 95% confidence intervals for children in England. Admission rates for boys and girls are shown separately.

Age variation in anaphylaxis

Variations in anaphylaxis admission rates based on the age of the child were further explored. All children in the dataset were divided arbitrarily into two groups: those aged 5 years or less, those aged between 6-17 years. The trends based on age and gender are shown in Figure 4-3 below. Boys aged 5 or less have higher rates of anaphylaxis admissions compared with girls. These differences in admission rates are not apparent in older children.



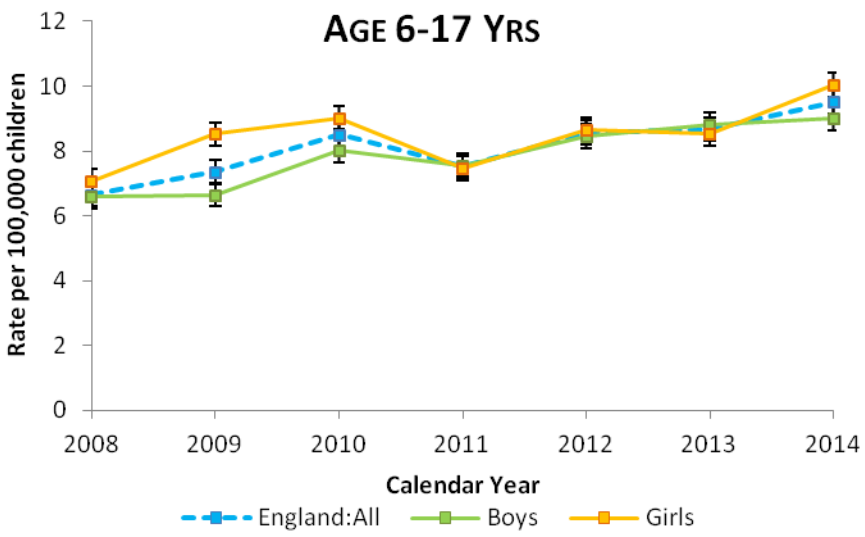


Figure 4-3: Age related differences in anaphylaxis rates: Anaphylaxis rates per 100,000 and 95% confidence intervals for children in England aged 5 years or less versus those aged 6-17 years.

Anaphylaxis- underlying aetiology

Figure 4-4 shows the underlying conditions that contributed to anaphylaxis amongst English children during the study period. Where the underlying allergen is neither food nor a drug (see Appendix Table 4.A for the relevant ICD-10 codes), the individual is classified in HES as having anaphylaxis due to unknown aetiology. Iatrogenic causes (i.e., treatment related causes) for anaphylaxis include reactions to drugs or serum.

Food allergens are the dominant cause for anaphylaxis amongst English children. Hospital related anaphylaxis, our data suggests, is very rare. There has been an increase in anaphylaxis rates due to food as well as due to unknown conditions during the study period.

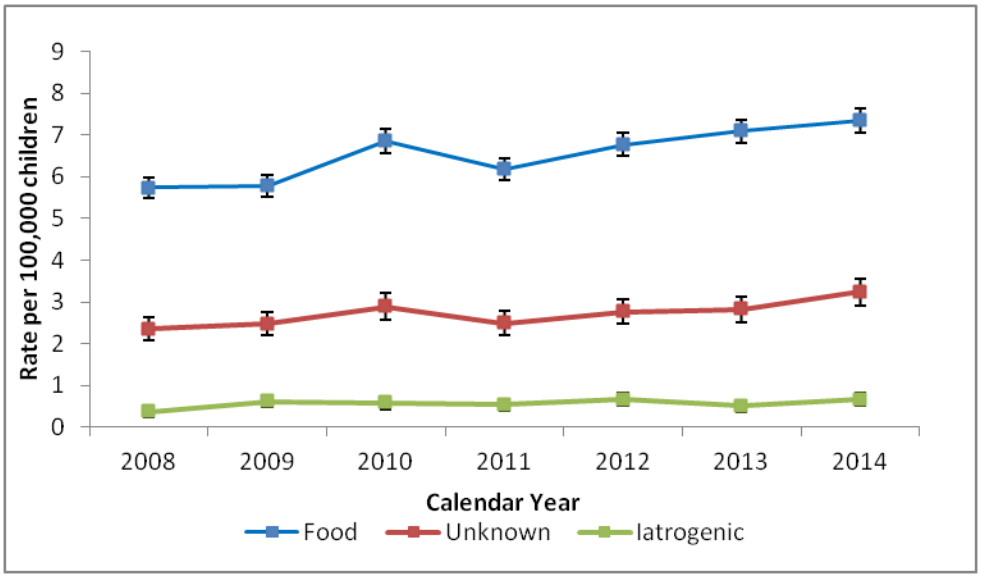


Figure 4-4: Anaphylaxis rates per 100,000 children (and 95% confidence intervals) in England based on the underlying allergic aetiology (2008-2014).

Table 4-1 shows the changes to admission rates for various emergencies in England. A notable finding is the fact that there has been up to a 50% increase in the number of children being admitted with anaphylaxis during the study period (i.e., a span of 7 years). The increase appears to be spread out amongst all age groups, although there is a suggestion that boys aged 5 years or less have had a higher increase than most others (see also Figure 4-3).

Table 4-1: Proportion change in the emergency admission rates for various allergic conditions amongst English children between 2008- 2014

	(n=) (2008)	Rate* (2008)	(n=) (2014)	Rate* (2014)	% change
Emergency Admissions	5372	47.95 (47.2-48.7)	8024	69.22 (68.2-70.3)	44.35 (44.21 - 44.50)
Anaphylaxis (All)	743	6.63 (6.2-7.1)	1113	9.6 (9.1-10.1)	44.77 (43.13 - 46.65)
Male	401	7.11 (6.4-7.8)	608	10.2 (9.5-11.0)	43.95 (41.70 - 46.67)
Female	342	6.37 (5.7-7.0)	505	8.93 (8.2-9.7)	40.16 (38.00 - 42.80)
Age ≤5 yrs	245	6.59 (5.8-7.4)	400	9.74 (7.9-9.6)	47.96 (44.45 - 52.42)
Age 6-17 yrs	498	6.66 (6.1-7.2)	713	9.52 (8.8-10.2)	43.10 (41.41 - 45.07)
Food related	642	5.73 (5.5-6.0)	851	7.34 (7.1-7.6)	28.10 (27.59 - 28.66)
Unknown aetiology	264	2.36 (2.1-2.6)	375	3.23 (2.9-3.6)	37.27 (34.97 - 40.19)
Iatrogenic	41	0.37 (0.3-0.5)	77	0.66 (0.5-0.8)	81.50 (70.02 - 103.07)
Urticaria	474	4.23	615	5.31	25.39
Angioedema	163	1.46	285	2.46	68.97

**Rate per 100,000 children*

4.6.2 Comparing emergency allergy admission rates for WM children with those for English children (2008 to 2014)

The admission rates for anaphylaxis were broadly similar in WM and England during the study period. The admission trends for urticaria, angioedema and anaphylaxis are shown for England and WM in Figure 4-5**Error! Reference source not found.**.

Admission rates for angioedema and urticaria have been increasing over the study period in England as well as the WM.

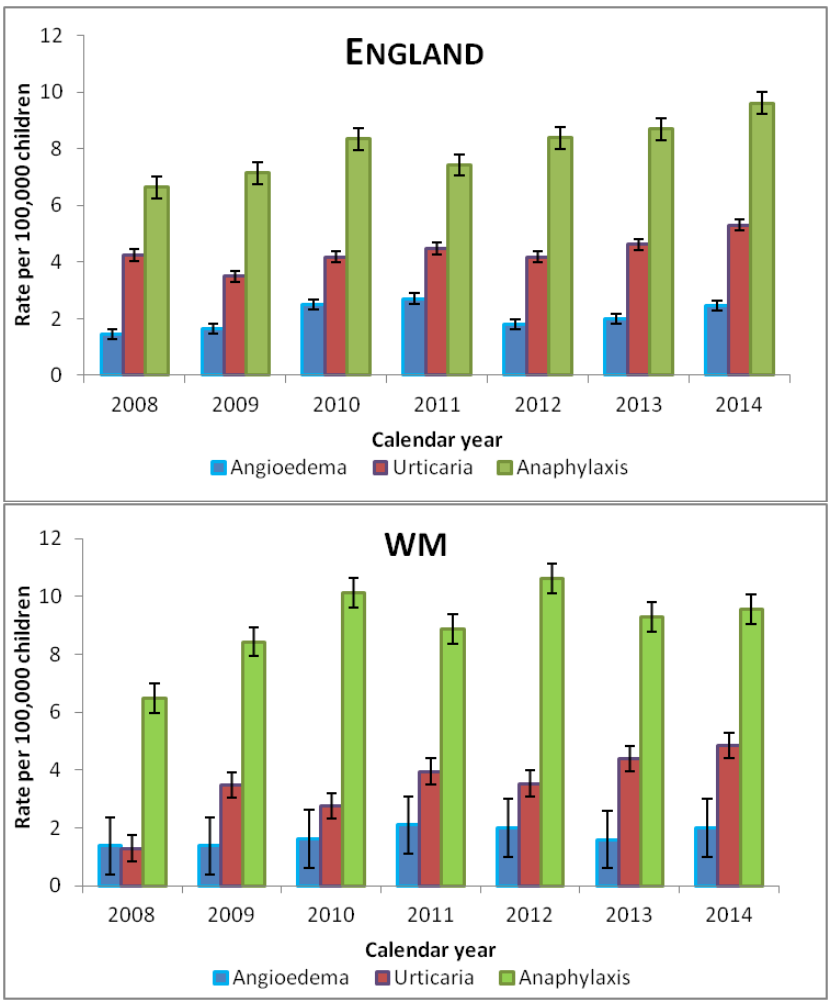


Figure 4-5: Emergency admission rates per 100,000 children for allergy related conditions, England versus WM. 95% confidence intervals are shown.

4.6.3 Elective admissions

Specific allergen Immunotherapy Treatment (SIT)

The trends in admissions for SIT (or allergen desensitisation treatment) in England and WM are shown in Figure 4-6. The rate of total appointments for SIT per year is compared with that for children starting treatment for the first time. The graph shows that the immunotherapy trends for WM are low compared with that of England overall.

Most of the SIT treatments offered to children were for allergic rhinitis. Figure 4-6 highlights the differences in treatment trends between England and WM. Although there has been an upward trend in the number of children being offered the treatment over the last few years, the overall rates remain low in the WM.

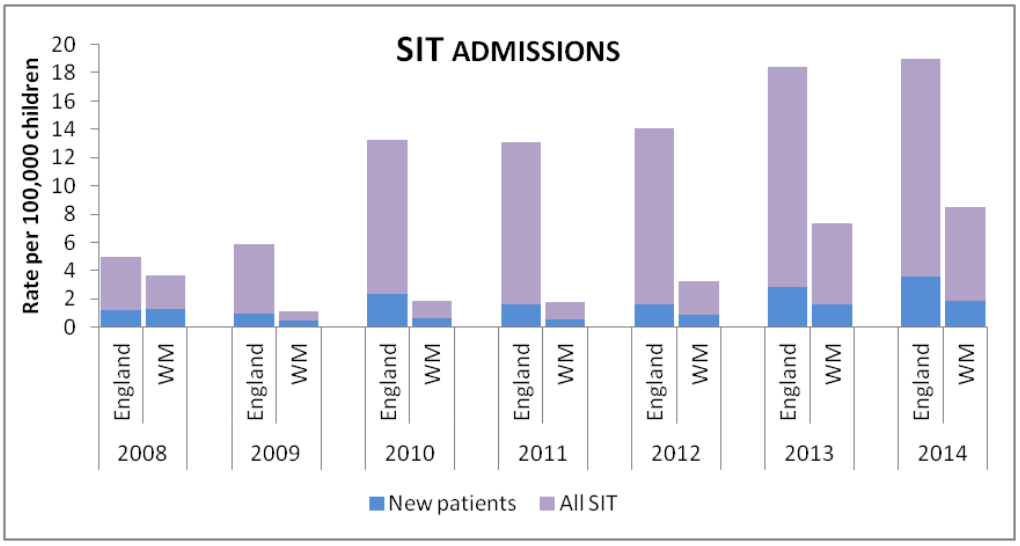


Figure 4-6: Differences in SIT treatment start rates for children in England vs WM. The rate for new treatments each year initiated is shown in blue.

The age trends in SIT in England are shown in Figure 4-7. A similar sub-group analysis was not carried out for WM given the relatively low numbers. More teenagers are being offered desensitisation in England, and there has been a decrease in the number of children aged 5yrs or under receiving these treatments.

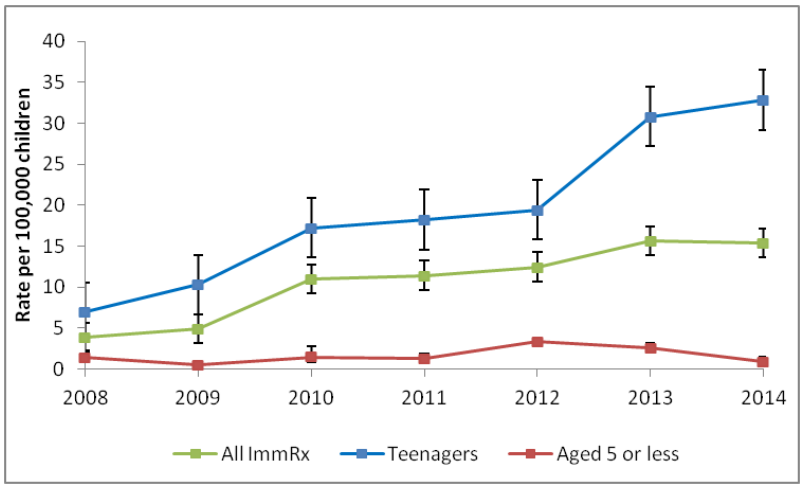


Figure 4-7: Age specific SIT treatment admission trends per 100,000 children in England. 95% confidence intervals are shown.

Changes in the proportion of children being electively admitted to the NHS for allergies are detailed in Table 4-2 and Table 4-3. The data show that although the admission rates for SIT have increased in the WM during the study period, the rates lag substantially behind those for England overall. This is true for both modalities (subcutaneous and sublingual) of immunotherapy and also for the diagnosis for which treatment is offered (allergic rhinitis vs. other).The number of children being offered SIT (new admissions) are also very low in the WM. In fact, the rates for children starting subcutaneous immunotherapy have fallen slightly in 2014 compared with 2013 (see Figure 4-6).

Table 4-2: Proportion change the specific immunotherapy admission rates in England for various allergic conditions between 2008- 2014

	Number (2008)	Rate* (2008)	Number (2014)	Rate* (2014)	% change
SIT	429	3.83 (3.5-4.2)	1789	15.43 (14.8-16.1)	303.01 (285.06 - 324.62)
Sublingual	234	2.1 (1.8-3.4)	337	2.91 (2.6-3.2)	39.2 (36.62 - 42.49)
Subcutaneous	195	1.74 (1.5-2.0)	1452	12.52 (11.9-13.1)	633.16 (562.88 - 694.62)
SIT (aged 13-17 yrs)**	227	6.94 (6.1-7.8)	1023	32.83 (31.0-34.6)	372.92 (343.73 - 410.34)
SIT (age ≤ 5yrs)**	51	1.37 (1.0-1.7)	37	0.90 (0.6-1.2)	-34.25 (-38.64 to -31.74)
New admissions	138	1.23 (1.1-1.4)	414	3.57 (3.3-3.9)	189.9 (160.33 - 181.64)
New admissions (SCIT)	49	0.44 (0.3-0.5)	233	2.01 (1.8-2.2)	359.54 (313.24 - 435.56)
New admissions (SLIT)	89	0.79 (0.7-0.9)	181	1.56 (1.4-1.7)	96.54 (85.62 - 111.74)
SIT- allergic rhinitis	367	3.28 (3.2-3.9)	1091	9.41 (9.1-10.2)	187.29 (160.33 - 181.64)
SIT- other	62	00.55 (0.4-0.7)	698	6.01 (5.58-6.45)	986.4 (833.70 - 1239.95)

Rate per 100,000 children* * these analyses were not carried out for WM due to low numbers*

Table 4-3: Proportion change in the specific immunotherapy admission rates in WM for various allergic conditions between 2008- 2014

	Number (2008)	Rate* (2008)	Number (2014)	Rate* (2014)	% change
SIT	29	2.35 (1.52-3.19)	84	6.68 (5.3 -8.07)	184.13 (152.98 - 249.70)
Sublingual	17	1.38 (0.73-2.03)	8	0.63 (0.2-1.08)	-53.84 (-46.87 to --73.14)
Subcutaneous	12	0.97 (0.43-1.52)	76	6.05 (4.73-7.37)	521.3 (384.97 - 1005.77)
New admissions	16	1.30 (0.86-1.73)	23	1.83 (1.19-2.47)	41.01 (37.50 - 42.76)
New admissions (SCIT)	9	0.73 (0.48-0.98)	16	1.27 (0.71-1.83)	74.39 (48.43 - 87.08)
New admissions (SLIT)	7	0.57 (0.23-0.91)	7	0.56 (0.4-0.72)	-1.91 (-21.02 to 73.61)
SIT- allergic rhinitis	20	1.62 (0.92-2.32)	66	5.25 (4.01-6.49)	223.71 (179.33 - 335.51)
SIT- other	9	0.72	18	1.43	96.19

**Rate per 100,000 children*

4.7 DISCUSSION

4.7.1 Principal findings

Admission rate

Our analysis found that there has been a steady increase in the rate of admissions for allergy and related conditions amongst children in England as well as the WM between 2008 and 2014. The rate of emergency admissions has increased, with nearly a 44% increase in the admissions for anaphylaxis; 25% and 69% increase in admissions due to urticaria and angioedema respectively in England during the 7 year study period. An increase in emergency allergy admissions in England was reported in previous publications [122, 133] and similar trends were reported from Australia [134]. Although the estimates in the current study are only for the paediatric population, the trends are in keeping with that from the published literature.

Anaphylaxis rates

Anaphylaxis rates appear higher for boys aged 5 years and under compared with girls- the reason for this is not clear. This gender gap in early years anaphylaxis has been previously reported in the literature [135]. Data from UK primary care presented in the previous chapter shows that boys are more commonly diagnosed with nut allergy, food allergy, ARC and asthma compared with girls. As discussed previously, hormonal causes and genetic causes have been suggested, but no definite reason for this gender gap has been found so far [74, 105]. Food allergy is diagnosed most frequently in the first 5 years of life and is the commonest cause for anaphylaxis amongst children, accounting for more than 60% of all admissions for childhood anaphylaxis. An increase in the prevalence of GP diagnosed food allergy amongst children was demonstrated in the previous chapter (Figure 3-9). This may be linked to the increase in anaphylaxis rates. Susceptibility to food allergies in early childhood, new research suggests, is likely due to skin exposure to food and can be modified by early dietary exposure to appropriate food allergens [136]. These findings can be used to potentially help reverse the current upward trends in childhood anaphylaxis.

Drug or serum induced anaphylaxis account for less than 10% of all anaphylaxis amongst English children, although the rate appears to be increasing over time. The trends in WM were similar to those seen in England. These data are in keeping with published literature [122, 128]. Some recent publications have suggested a significant difference in anaphylaxis rates based on ethnic origins of the population [123], but detailed analysis using ethnicity data was not possible using HES.

Elective admission

Allergen specific immunotherapy (SIT) has been shown to be clinically effective and cost effective in the management of allergic rhinitis [137] and also in the management of individuals with severe anxiety following anaphylaxis due to wasp or bee stings [138].Elective admissions for allergy, especially those for SIT (specific immunotherapy or desensitisation treatments) have been steadily increasing between 2008 and 2014. SCIT (injection based SIT) appears more popular for treating children with allergies in England. The rate of SLIT (tablet based SIT) related admissions have remained stable over the period 2008-2014 in England. The low numbers may reflect the fewer number of admissions required for SLIT therapy. Whereas multiple treatments in the hospital or clinical setting are required for SCIT therapy, SLIT typically requires only a few hospital visits (sometimes just 2 per year). Nevertheless, this discrepancy is still evident when only new patients being offered the treatment are considered. This preference for SCIT is interesting since there is no evidence to support its efficacy over SLIT in children [139]. The use of SCIT is highest in adolescents (aged between 13 and 17 years), although our data suggests that children under the age of 5 are also being offered this treatment in England.

Our data suggests that SIT is underused for children within the WM. Fewer children are started on desensitisation therapy in the WM compared with the average for England overall. The proportion of children being offered desensitisation for allergic rhinitis in the WM also compares poorly with the English average. This is especially pertinent, given the higher rates of ARC amongst WM children compared with the rest of the UK (Figure 3-16). The

increasing trends in SIT for children in England are encouraging and suggest that there is a trend towards improved management of children with allergies. Nevertheless, the overall rates for SIT in England are still very low. Less than 1:600 children who present to their general practitioners with allergic rhinoconjunctivitis are offered this treatment in England and the rate in WM is less than 1:1800. This suggests either that the children in WM have much less severe disease compared to their counterparts across the country or that they do not have adequate access to specialist services. The former scenario is unlikely, given that there is no difference in the emergency admission trends for allergy in the WM compared with rest of England. Heterogeneity in coding may be another possible explanation [140], although this is unlikely to exclusively affect the WM region. SIT is only offered in specialist centres in the UK [141]. Difficulty in accessing specialists is the most likely explanation for these very low SIT rates. The problems with specialist access appear to be particularly severe for children in the WM.

4.7.2 Strengths and limitations of the study

The strength of this study is that it is the first to look specifically at the trends in paediatric allergy admissions using HES database. The analysis also looked at various subgroups of children (such as boys versus girls, children aged 5 years or less versus 6-17 years) in addition to estimating regional trends in admission rates for allergy (i.e., those from the WM region). This is also the first study, to our knowledge, to analyse trends in SIT across England using HES database.

There are some limitations of this study. For the purposes of this analysis, we assumed that HES data coding was accurate. HES database is used for purposes of reimbursement (although this analysis did not use PbR data) and hence it is likely that the data collection is fairly complete. However, like any other large health dataset, coding in HES can be inaccurate [140, 142]. Anaphylaxis, in particular, is often miscoded [123] and the codes available are limited (for example, there are no codes for insect venom related anaphylaxis). Also, HES does not record diagnoses for outpatient episodes. Accident and Emergency data are also not

recorded within this database. Children presenting with acute allergic conditions such as urticaria and angioedema are often managed in Accident and Emergency departments and discharged. Hence this analysis does not fully estimate the burden posed by paediatric allergy on NHS secondary care.

Despite all these limitations, HES remains the largest dataset for hospital admissions in England and Wales. Clinicians are generally aware of the importance of the dataset and are keen to be engaged in the collection and usage of these data [143].

4.7.3 Strengths and limitations in relation to published studies

There have been previous publications looking at anaphylaxis rates in the English population using the HES database [122] and the HSCIC has published an allergy special analysis report in 2014 which estimated emergency and elective admissions for allergy [128]. Our findings are consistent with the results of these two publications.

4.7.4 Areas for further research

Further research looking into the pathways of patients admitted for emergencies into the NHS (before and after admission) may be helpful in understanding efficiency of the available NHS primary care and specialist allergy services. In addition, analysis of outpatient and Accident and Emergency data will also help in the understanding of the extent of the problem.

4.7.5 Summary of database analysis

Chapters 3 and 4 demonstrate that there has been increasing demand on the NHS primary and secondary care services for paediatric allergy. Prevalence of GP diagnosed allergies has been steadily increasing as is the rate of elective and emergency admissions into NHS hospitals for allergy and related illnesses. Rate of complex allergies amongst children is also increasing. Whilst the trends in allergy prevalence are similar in the UK and the WM, allergic rhinoconjunctivitis is more commonly diagnosed in WM children.

Data from HES highlight the deficiencies in primary and secondary care provision for paediatric allergies. The rates of anaphylaxis are increasing; and emergency admissions for

urticaria and angioedema are also on the increase. Urticaria and angioedema can, in a majority of cases, be managed effectively in primary care with appropriate use of antihistamines and other drugs [144]. Provision of tailored individual management plans can help reduce the occurrence of anaphylaxis in vulnerable children [145].

The provision of SIT can be used as a proxy for specialist access to allergy services, given that SIT is only offered by specialists in the UK. Increases in SIT rates for allergic rhinitis and other conditions are encouraging and suggest that more children are receiving these treatments where appropriate. However, the number of children being offered these treatments is very low in England as a whole. Considering that not all children with allergic rhinoconjunctivitis consult their general practitioners in the first place, it is reasonable to assume that most of the children presenting to the GPs have at least moderate symptoms. Despite this, less than 1:600 children in England (and even fewer children in WM) have received SIT in 2014. Allergic rhinoconjunctivitis in children is an often ignored issue which can have significant implications for exam performance, career [146] and quality of life of the individual [147] and considerable societal economic costs [148, 149]. SIT is a disease modifying treatment modality for ARC and is cost effective [150]. Better service pathways will help improve access to this treatment.

4.8 CONCLUSIONS

Demand on NHS primary and secondary care due to paediatric allergy and related conditions is increasing. Whilst the prevalence of GP diagnosed allergic rhinoconjunctivitis, eczema, food allergy and drug allergy is on the increase, the prevalence of asthma has been stable amongst children between 2000 and 2015. The prevalence rate of complex allergies is also increasing. These UK trends are mirrored in the WM. Emergency admission rates for anaphylaxis, urticaria and angioedema are also increasing in England and the WM. Allergen specific immunotherapy rates for children are poor in England with a very small proportion of children diagnosed with ARC receiving this treatment, reflecting the paucity of allergy

specialists across the country. Given the severe shortage of paediatric allergists in the WM, the SIT rates for this region are even lower.

Analysis of these databases has revealed that there may be issues with access to secondary care services for paediatric allergy, particularly in the WM. In order to explore this further, a qualitative study was planned. This is discussed in the next chapter.

5 A Qualitative Study to Understand Parent Experiences with Paediatric Allergy Pathways in the West Midlands

Analysis of the primary and secondary databases discussed in the previous two chapters has suggested that there are barriers to accessing specialist services for children with allergies, particularly in the WM region. In order that the current pathways may be better understood, talking to parents who had experienced these services was necessary. Hence, a qualitative study was planned to ascertain parent experiences with paediatric allergy services in the WM. The methodological basis for qualitative studies, the objectives of the study and the findings are discussed in this chapter.

5.1 INTRODUCTION

Allergy services in the UK are clearly very heterogeneous (as discussed in Chapter 2) and are perceived as being ineffective in combating the 'allergy epidemic' [7]. Previous publications have suggested that specialists in allergy, particularly paediatric allergy, are in short supply [114]. In addition, general practitioners feel especially anxious about managing children with allergies [151].

In the WM, allergy services for children are offered in 12 NHS hospital trusts (See Section 1.2). The population of the county is currently 5.6 million - roughly a tenth of the population of England- and service pathways for the region are disparate. This is partly because of the unique ethnic mix of the region and also the variations in urban/ rural services. In addition, most of the specialist allergy services for the region are concentrated in larger, urban centres.

In order to explore and understand what parents thought about the existing paediatric allergy services in the WM, a qualitative study was planned. Since parents access healthcare on behalf of their children, semi-structured interviews with parents of children attending 2 specialist clinics (Royal Shrewsbury Hospital in Shropshire and Birmingham Heartlands Hospital in Birmingham) were carried out. Choosing parents attending specialist allergy clinics provides relevant information regarding the entire allergy care pathway (primary and secondary care) in the WM, thus providing a fairly comprehensive view of the positive and negative aspects of the service.

Data obtained from this qualitative study will provide attributes for the planned discrete choice experiment (DCE), which aims to obtain preferences from an unselected group of parents within the Midlands region. The DCE is discussed in detail in Chapter 6.

In this Chapter, after a brief introduction to the principles of qualitative research, the methods employed for this particular study will be presented. The results obtained will be discussed and existing literature will be used to help contextualise the findings. The Principal

investigator (LD) will reflect on the influence of her experiences as a consultant immunologist on her role as a researcher during the interviews as well as during the analysis of this study.

5.2 QUALITATIVE RESEARCH

Qualitative research has its origins in social science theory and considers the following:

- *Ontology* - the reality of what exists and what should be studied,
- *Epistemology* - what can be studied and how can we study this
- *Methodology* -the techniques that can be used to obtain this knowledge [152, 153].

Qualitative research can be broadly defined as ontological and epistemological approaches that are "directed at providing an in-depth and interpreted understanding of the social world of the research participants by learning about their material and social circumstances, their experiences, perspectives and histories" [154]. The aim is, therefore, to obtain knowledge regarding behaviours, perceptions and experiences of individuals which are intangible in quantitative research. The focus is on questions such as "why" or "how" rather than "how many" [155].

In keeping with this difference in focus, there are differences in

i. recruitment
ii. data collection and
iii. data analysis techniques

between qualitative and quantitative research. These will be discussed briefly below.

5.2.1 Recruitment in qualitative research

Subject recruitment in qualitative research is substantially different from that of quantitative research. Whereas in the latter the emphasis is mostly on avoiding selection bias and selecting a probabilistic (random) but representative population for the study [156], recruitment for qualitative studies is usually non-probabilistic and aimed at best ascertaining elements of particular interest to the researcher [154]. This is appropriate since interviewing

individuals without any knowledge of the subject of interest is unlikely to yield useful information. Subjects are generally chosen not to be representative of the population, but because they possess characteristics relevant to the study [157].

Qualitative sampling can be purposive or criterion-based (i.e. chosen because of characteristics that allow detailed exploration of themes of interest to the researcher), convenience based (i.e., chosen according to ease of access to the researcher without any definite sampling strategy), opportunistic (flexible recruitment based on opportunities that arise during field work), snowball sampling (using initial recruits to identify further respondents for the study) [154, 158] . Theoretical sampling is a form of purposive sampling used in the development of grounded theory wherein each interview is analysed before the next interviewee is chosen in order that emerging theories or ideas can be developed and refined [154]. Very often, studies use a combination of these techniques to recruit subjects into their studies.

Sample size in qualitative studies, therefore, is not decided prior to the start of the study on the basis of tests for statistical significance. It is determined on the basis of saturation, i.e., no new themes emerge from further interviews. The definition of saturation can differ based on the study protocol and objective [159].

In this study, sampling was purposive- i.e., parents were chosen in order that a broad range of allergic conditions and ages of children could be represented within the study. Recruitment was opportunistic and varied based on the clinical pressures within the outpatient department on a given day.

5.2.2 Data collection in qualitative studies

The ways in which data are collected and analysed are determined by basic epistemological assumptions and the characteristics of the researcher. Depending on the study objectives, data can be collected in

- Single research episodes, such as:

  - in-depth individual interviews
  - focus groups – where a group of individuals discuss the topic of interest with the researcher recording and facilitating the process
- Longer term studies, for example:
  - ethnographic observations- where the researcher observes subjects in their natural environments for a period of time
  - panel studies - data is collected over time using the same cohort of participants to understand the impact of change (e.g. an intervention)

Typically, sample sizes in qualitative studies are small since vast amounts of data can be obtained from even a limited number of participants. There are no set criteria for determining sample sizes- it is largely a matter of judgement, although some guidance has been provided [154]. Drawing meaningful conclusions from very small samples can be difficult, just as ensuring detailed analysis of large samples can be challenging [160]. Sample sizes, therefore, vary depending upon the purpose of the study; For example, studies aimed at developing new social theories (grounded theory) carry out data collection alongside analysis until there is data saturation - i.e., no new concepts emerge with subsequent units of data collection [161]. Ethnographic studies, in which the investigator becomes a participant within the community being investigated in order to gain an in-depth insight into their behaviours and beliefs, may need significantly more units of data collection. On the other hand, phenomenological studies (which aim to understand experiences from a subjective point of view) may require fewer participants [160] depending upon the study objective.

Interviews typically consist of open-ended questions, based on a guide which is designed to ensure that the topics of interest to the interviewer are covered. The questions serve to keep the interview focused on the topic, whereas the content of the interview is driven by the interviewee. As far as possible, leading questions are avoided and the participant is allowed to steer the conversation within the bounds of the topic. Interviews are usually audio (or video) recorded with the consent of the interviewee and the interviewer typically notes down salient

behavioural or contextual observations that may be useful during analysis [153]. Audio recordings are then transcribed with a view to preserving the naturalness of the speech and the interview as much as possible. The transcript should be an exact reproduction (verbatim) of the interview and should be suitable for the use of any researcher- even those not directly involved with the study [162].

In this study, one-off semi- structured interviews of eligible parents were carried out by the principal researcher (LD). Interviews were audio recorded and later transcribed verbatim by an external transcription agency. Some of the field notes jotted down by the researcher were also used in the reporting of the results (for example, comments made after the audio recording was stopped.)

5.2.3 Analysis of qualitative data

Analysis in qualitative research depends upon the study objectives and the ontological and epistemological stance of the researcher. In any qualitative analysis, transcripts need to be read repeatedly until the researcher is very familiar with the data. It is often recommended that interim analyses be carried out during data collection to ensure that the emerging avenues of inquiry are identified and pursued appropriately [163].

Qualitative data can be analysed in many different ways. For example- narrative analysis places emphasis on the way individuals use language to interpret and narrate their experiences [164]; discourse analysis concentrates on spoken and written language and its importance in the understanding of cultural perspectives and identities [165]; thematic analysis is a method "for identifying, analysing and reporting patterns or themes within data" [166]. Grounded theory, on the other hand, is dedicated to discovering new concepts embedded within the data. This is possible by constantly comparing concepts across subjects and dimensions in an iterative fashion, with data analysis being carried out continuously alongside data collection [161].

Identification of codes or themes in qualitative analysis can be either inductive (i.e., derived de novo from the available data) or deductive whereby codes are decided a priori with the help of available literature or expert knowledge. Whereas some methods- such as grounded theory- would necessarily require all coding to be inductive, others such as thematic analysis are more flexible and can accommodate both types of coding systems.

Framework analysis falls under the broad umbrella of thematic analysis in qualitative research. Its hallmark is the 'matrix output' which consists of cases and codes organised in rows and columns respectively [167]. Such organisation of data facilitates 'constant comparison', an iterative process that allows the researcher to compare data across as well as within cases in order to develop codes, conceptualise subject matter of the interviews and to understand the relationship between various codes/ categories [168]. Framework method can accommodate both inductive and deductive approaches to coding and is not wedded to a particular theoretical or philosophical approach to qualitative analysis [167]. Such flexibility is important in order that participants can express their views on topics that the interviewer may not have originally anticipated, but may be important to the research topic.

In this study, framework analysis was employed and data were distributed into themes which were derived both de novo (inductive) and a priori (deductive).

5.2.4 Comparison with quantitative studies

On the surface, qualitative research can be perceived as vastly different from quantitative research. The 'laxity' around recruitment and lack of structure during interviews, may appear lacking in rigor and probity. However, this is not the case. As with any research, the value of outputs from qualitative research will depend upon the appropriateness of the data being collected to the questions being asked [157]. The advantage of purposive sampling for interviews is that it allows for wider exploration of particular aspects that have been identified during the research. This can, to some extent, avoid selection bias that arises from using a convenient sample for research [157].

Both qualitative and quantitative methods, therefore, are important in academic research and carry their own advantages and disadvantages. Indeed, they can be used in combination to provide a wealth of data, especially in hitherto unexplored areas [155]. For example, an analysis of a national registry of individuals with food related anaphylaxis revealed a higher risk amongst adolescents [169]. The reasons for such an increase were then explored using a qualitative study which showed that some adolescents with food allergy do not perceive their allergy as a significant problem and that at least in some cases such an attitude stemmed from a lack of memory of their original allergic reaction [170]. Such information can be useful in creating targeted educational campaigns.

The data obtained from the current qualitative study will be used to develop attributes for a Discrete Choice Experiment (discussed in Chapter 6) which aims to understand and rank the preferences of parents for allergy services within the WM region.

5.3 METHODS

5.3.1 Centres and participant selection

This study included parents of children who were seen at two specialist allergy clinics within the WM region namely, the Royal Shrewsbury Hospital in Shropshire (semi-rural location) and the Heartlands Hospital in Birmingham (an urban location). These centres were chosen since they are geographically sufficiently separated (see Appendix Figure 1.A) to prevent overlap of services and experiences. In addition, both these centres are secondary referral units for allergy and thus parents attending these would have had experienced primary and secondary care services for their child's allergy.

Royal Shrewsbury Hospital

The Royal Shrewsbury and Telford Hospitals NHS Trust are the main providers of acute medical care for about half a million people in the North Western region of WM. The Paediatric allergy clinic is staffed by two experienced clinical nurse specialists who have had post graduate specialist training in allergy. The service is outpatient based and clinics are carried out at both Shrewsbury and Telford sites.

The service provides clinical assessment, diagnostic testing, challenge testing for children with suspected (or confirmed) allergies. There is also access to a dietician with specialist interest in allergy and the opportunity to refer patients to other related specialisms (e.g. dermatology, ENT, ophthalmology, gastroenterology) where appropriate. There is a visiting allergy consultant who assists twice a year to help out with the most complicated patients. There are no facilities for desensitisation treatment for children and Adult allergy services are not offered at this centre.

Birmingham Heartlands Hospital

The Heart of England NHS Foundation Trust based in Birmingham is one of the largest Hospital Trusts in England. It includes Birmingham Heartlands Hospital, Solihull Hospital and Community Services, Good Hope Hospital and Birmingham Chest Clinic and serves around 1.2 million people in and around Birmingham.

Paediatric allergy clinics are manned by two experienced, trained paediatric nurse specialists and a consultant paediatric immunologist. Outpatient services are offered for paediatric allergy at Birmingham Heartlands hospital, Solihull hospital and the Birmingham chest clinic, including clinical assessment and diagnostic testing with challenge testing for children with suspected (or confirmed) allergies weekly. There is also access to a dietician with specialist interest in allergy and the opportunity to refer patients to other related specialisms (e.g. dermatology, gastroenterology, respiratory, ENT, ophthalmology) where appropriate. Additionally there is provision for desensitisation treatment to grass pollen and facilities exist for transition to adult allergy clinics for older children.

Participants

Parents aged at least 18 years or over with children aged between 0-16 years were included. The children should have a confirmed diagnosis of allergy or allergic disease. Parents aged less than 18 years of age, and those unable to provide informed consent or unable to understand or converse in English were excluded.

This study was given ethical approval by the Newcastle and Northtyneside1 National Research Ethics Committee (NRES) [Application number: 14/NE/1060] and was sponsored by the University of Birmingham. It also received approval from the Research and Development units of the respective hospitals. It was accepted as a portfolio study by the NIHR Clinical Research Network (UKCRN ID 16953). The approval document is included in the appendix (5.A).

Participants were recruited from these clinics opportunistically. Sampling was purposive- participants were chosen in order that a broad range of allergic conditions, as well as patient age group were represented [157].

The study was carried out in two phases; 6 interviews were carried out in phase 1 (between Sep 2014 and Dec 2014) and 12 interviews were carried out in phase 2 (between Jan 2016 and Jun 2016) to accommodate parental leave taken by the researcher (LD). There were no notable changes to either of these services during this period. No additional staff were recruited, nor did any staff member leave during this period.

Parents were invited by the clinical staff in either of the two recruiting centres to take part in the study. They were provided with verbal information regarding the study and with an information sheet (Appendix 5.B). If they were interested in taking part in the study, they were advised to sign a consent form (Appendix 5.C) and to also complete a demographic information form which included questions regarding age of participant, age of the child, allergies, contact details etc. (See Appendix 5.D). The interviewer (LD) contacted the parents by telephone to further explain the study, to confirm the consent and to arrange for a suitable time and place to carry out the interview. Parents could choose between telephone or face-to-face interviews as per their preference.

Two interim analyses were carried out during the project (Dec 2014 and then in Apr 2016) to choose characteristics of further participants and to amend the interview guide in order to include emerging themes and also to capture a wider range of experiences within the study.

Participants were informed that they could withdraw from the study before, during or after data collection. Recruitment was continued until no new themes emerged from further interviews i.e., until inductive thematic saturation was achieved [159].

5.3.2 Interviews

Interview guide

Interviews were semi structured and were carried out using an interview guide (Appendix 5.E). The guide was developed by the principal researcher (LD) based on her clinical experience and in consultation with PhD supervisor (Dr Carole Cummins), paediatric consultant colleagues (Dr Scott Hackett at Heartlands Hospital and Dr Martyn Rees at Royal Shrewsbury Hospital), and colleagues within the Institute of Applied Health Research at University of Birmingham.

The topic guide covered a range of issues which were felt to be important in order to understand the experiences of parents whilst accessing primary and secondary care services for their child's allergy. Questions relating to initial symptoms of allergy, experiences with primary care, issues with access to GPs (if any), referral to secondary care, experiences with emergency services (if applicable), experiences with secondary care, suggestions for service improvement (if any) were included.

Following the interim analyses, modifications were made to the interview guide in order to explore emerging themes (e.g. issues with labelling, costs etc. for children with food allergies, effect of allergy on the child/ family).

Interviews and transcription

Interviews were carried out either face-to-face or over the telephone as per the participants' preference. Interviews lasted between 30-75 minutes and all interviews were carried out by the principal investigator (LD).

Interviews were audio recorded with the parent's consent and were transcribed verbatim by an external transcription company approved by the University of Birmingham. A comprehensive confidentiality agreement was provided by the company which was

considered appropriate for the study. Each transcript was checked for accuracy against the audio files by LD.

5.3.3 Analysis

Data in this study were analysed using the Framework method as described by Gale et al [167].

Given that the study was aimed at understanding experiences of parents with primary and secondary care services in the WM region, certain codes were deduced based on study objectives (e.g. preferences for clinician seen in secondary care, access issues with primary and secondary care) whereas others (e.g. effect of allergy on child/ parent/ family; activities affected by allergies such as shopping/socialising/eating out; being taken seriously by physicians) were derived from the data.

Recruitment was continued until it was felt that no new themes were emerging from further interviews. The transcripts were analysed using the NVivo 11 software. Transcripts were read and re-read before classification into broad themes. These were then reviewed in order that the codes could be further refined and a relationship between various themes could be deciphered. Some transcripts were coded independently by other researchers within the health economics unit (Drs Louise Jackson and Hareth Al-Janabi) and discussed in order to ensure consistency in coding.

5.4 RESULTS

A total of 18 parents were interviewed, 11 were recruited from the Royal Shrewsbury Hospital and 7 from the Birmingham Heartlands Hospital. Most parents were aged between 26-40 years (see Table 5-1) and almost all (17/18) were mothers. The ages of children ranged between 7 months and 16 years and a wide range of allergies and related diagnoses were covered as shown.

12 interviews were carried out over the telephone and 6 were conducted in the home of the interviewee (as per the preference of the interviewee).

Table 5-1: Details of the interviewees

No	ID	Interview*	Parent age	Child age	Allergy
1	P 01	Direct	26-40 yrs	1-5 yr	Eczema, nut
2	P 03	Direct	26-40 yrs	<1 yr	egg
3	P 06	Direct	26-40 yrs	1-5 yr	Milk, soya
4	P 07	Telephone	26-40 yrs	1-5 yr	eczema, asthma
5	P 08	Direct	26-40 yrs	1-5 yr	Plum
6	P 09	Direct	26-40 yrs	<1 yr	Multiple food intolerances
7	P 11	Telephone	26-40 yrs	1-5 yr	Eczema, milk intolerance
8	P 12	Telephone	26-40 yrs	1-5 yr	Nut allergy;
9	P 13	Telephone	26-40 yrs	5-10 yr	Egg, peanut allergy
10	P 14	Telephone	41-55 yrs	1-5 yr	Peanut, baked beans, egg
11	P 15	Telephone	41-55 yrs	14 yr	Peanut and macademia
12	P 16	Telephone	41-55 yrs	< 1 yr	Milk, egg and wheat
13	P 17	Telephone	26-40 yrs	1-5 yr	Peanut
14	P 18	Telephone	41-55 yrs	10-15 yr	sesame
15	P 19	Direct	26-40 yrs	1-5 yr	Egg
16	P 20	Telephone	41-55 yrs	10-15yr	Peanut, cat, dog
17	P 21	Telephone	41-55 yrs	>15 yr	Hay fever
18	P 22	Telephone	41-55 yrs	10-15 yr	Dairy, egg, sesame, nuts

*Direct refers to a face-to-face interview

Detailed analysis of the interview transcripts resulted in the identification of the following themes.

1. Initial symptoms of allergy
2. Previous experience with allergy
3. Experiences related to allergy services
4. Effect of allergy on daily living

5.4.1 Theme 1: Initial symptoms of allergy

There was a wide variety in the presentation of allergy amongst children whose parents were interviewed for this study. Symptoms were sometimes very typical of allergy and parents found it easy to link the symptoms with a trigger.

"*So when she was about seven to eight months old, I gave her some scrambled egg. She ate the egg, to begin with, and then about five minutes later she started to struggle to breathe and she started to go very red.*" [P13; 6 yr old with egg and peanut allergy]

"...he must have been about two-ish and had a piece of bread that had a few sesame seeds on the, the crust and just had a reaction with hives around the mouth and sort of itchiness and that kind of thing, which was then later confirmed with skin prick tests in hospital." [P18; 11 yr old with sesame allergy]

In some instances, although children had fairly severe symptoms over a long period of time, it was difficult to obtain a diagnosis, much to the parent's distress.

"*Every single bottle he had, we had projectile vomiting, diarrhoea. He was never settled in between his bottles. He would scream throughout the feed. We'd had him physically arching and screaming and clenching with his stomach. It was frightening ..."* [P6; one year old with milk allergy]

5.4.2 Theme 2: Previous experience with allergy

Allergy often manifests quite unexpectedly and can be very distressing at presentation. This is especially true when parents feel at a loss to explain the sudden deterioration in their child's health, since this adds a lot of uncertainty into their daily lives. Some parents had already, however, had some experience with allergy, usually since other family members had experienced similar symptoms. This sometimes gave them extra confidence in diagnosing and managing their own child's allergies.

"... my dad is a hay fever sufferer, my sister has hay fever and is asthmatic and so, being familiar with it in the family, [I] sort of picked up on it as soon as she sort of started with the

same thing, ...each sort of summer it would re-appear so, you know, we were fairly sorted that it was hayfever ..." [P21; 16 yr old with hay fever]

"*having had an older son with food allergies and suffering with allergies myself, I kind of knew ...[what to do]"* [P18; 11 yr old with sesame allergy]

"...it helped that my husband had got eczema as well because he knows how to recognise when there's flares going on, he knows when to kind of step in when there's a reaction happening and give antihistamines and things like that, so that was good." [P1; 5 yr old with eczema, egg and peanut allergy]

Others specifically were worried because of lack of such experience:

"because I don't know anybody with an allergy, well, nor does my husband. It is all very new territory, so it's a bit like nerve-racking I guess and we're worried about her obviously" [P17; 3 yr old with peanut allergy]

The reasons for developing allergies were speculated upon. Some parents were anxious about their children directly inheriting allergies given that there were other members within the family with these problems. This caused them to access healthcare for clarification, although no specific allergy symptoms were manifested by the child.

"..he hasn't had a reaction to nuts because as far as I'm aware I've never exposed him to nuts, because my husband's allergic to nuts we don't really have nuts in the house. And because I'd kind of, wasn't 100% sure whether my husband could have passed it on to him...." [P7; 3 1/2 yr old with eczema and asthma]

Parents with allergies and related conditions assume responsibility and feel guilty when their children do manifest the symptoms.

"I think my husband was just particularly disappointed because he knew what it was like to live with it and probably felt a bit guilty that he'd passed that on to [our son]"[P1; 5 yr old with eczema, egg and peanut allergy]

5.4.3 Theme 3: Experiences relating to allergy services

Since all the parents included in our study were already reviewed in the specialist clinic, they all had experienced primary and secondary care services for allergy in the region. We asked them questions specifically aimed at ascertaining their opinions and experiences with these services.

Analysis of the data revealed 6 sub themes directly related to allergy services. These included:

i. Being taken seriously
ii. Receiving timely and appropriate health care
iii. Clinician seen in hospital
iv. Support with allergy management
v. Issues with information
vi. Suggestions for improvement

Each of these sub themes are discussed in detail below.

i. Being taken seriously

Parents whose children had allergies valued having a mutually respectful relationship with their doctor- especially their General Practitioner, who was usually their first contact with the health care system. They felt thoroughly distressed when they perceived the attitude of the doctor as dismissive.

"..I think he was about eight weeks old when I first went to the doctor and just got fobbed off left, right and centre because he hadn't got a rash.... " [P6; one year old with milk allergy]

".. in the early weeks, it was just being put down to, 'Maybe you've got a milk imbalance or something,' and nothing was really taken seriously." [P9; 8 month old with multiple food intolerances]

"I don't really feel like my GP has been part of this journey .. in fact, the first GP I saw sort of tried to downplay everything..." [P14; 5 yr old with peanut, beans and egg allergy]

On occasion, parents felt that poor advice from their doctor could have harmed their child.

".. he [the GP] said, with regards to whether it was nuts or not, he wasn't sure but if we wanted to, we could try it again -which was a bit of ropey advice - but we actually did and it did come up again badly, so we avoided any nuts in the house." [P17; 3 yr old with peanut allergy]

"the lady doctor that I saw said 'oh, no, she needs to have at least four or five episodes [before we refer]' …. but because she[the child] was so bad, I didn't wanna run the risk of giving it to her just for her to have another episode so we could say 'yes, it's definitely egg or not it's not egg' so I just cut out egg." [P19; 20 month old with egg allergy]

Such experiences meant that the parents felt the need to look for alternate avenues for better advice or management of their child. Sometimes this involved seeing different GPs within the same practice, even if this meant waiting a few extra weeks.

"…I suppose if I want to be diplomatic about it, there are GPs that I would prefer to see as opposed to one or two others. Some are quite dismissive. " [P11; 2 yr old with eczema and milk intolerance]

"... because the Doctor I wanted to see that, he was one of the children's Doctors, you know, she's seen right from being little, I normally have to wait, maybe 3, 4 weeks but that's because I want a specific Doctor ..because that's who [the child] been seeing all along." [P21; 16 yr old with hay fever]

This was also sometimes true of secondary care services. On occasion, when parents were reviewed in a specialist clinic, they came away confused and feeling that the condition and tests have not been fully explained. This caused a feeling of anxiety and frustration.

"Yeah, so we went in for these tests and they said, 'Yes, he's allergic to nuts probably. Bye, bye and good luck. Hope you work it out. I hope he doesn't die from a nut, you know,

thing'. That, that's, that's kind of how I felt. Not – they weren't like that but.. overall nothing was explained terribly well." [P14; 5 yr old with peanut, beans and egg allergy]

Sometimes, the parents felt that there was a disconnect between their anxiety for their child and the attitude of the physician towards the condition. This could sometimes be reassuring, but did cause frustration on other occasions.

"I guess it kind of felt like it wasn't a big deal because he[the specialist] sees it every day; whereas, obviously we're like worried parents.." [P17; 3 yr old with peanut allergy]

"I'd come out sometimes and I'd be so frustrated because I felt like, 'You weren't listening'. They [the GPs] just wouldn't listen to me. It was as if – you know, 'You're just an overreacting mom'." [P6; one year old with milk allergy]

Parents greatly valued having doctors acknowledge their 'gut instincts' with regards to the wellbeing of their children.

"finally the one lady doctor I insisted on seeing at her surgery said, 'Well, yes. I've got medical qualifications but where your child's concerned, you're the expert', which I finally thought, 'Well, yeah. I do know him' and I know – like I say, I know feeding patterns and I know normal" [P6; one year old with milk allergy]

"He [the GP] just said, if ever you reach the point where it's interfering with life or that there's too much going on...., come back because I can always refer her, and we can just get it sorted out once and for all." [P21; 16 yr old with hay fever]

When the parents felt 'listened to' and that their GPs were sympathetic, they were generally accepting of the treatment and management plans, even if they were not always convinced about their efficacy.

".. I didn't feel at any point that when I went it was like, oh it's not you again. Because at one point, I did go quite often. I'd say definitely with the E45 I thought, because that's the first one I got, I thought well that's not eczema cream, but I can't really fault them for trying the different creams." [P7; 3 1/2 yr old with eczema and asthma]

"..... yeah, [the GPs] are helpful. They're trying to find the different creams and all the rest of it, but I think it's quite an inexact science in terms of what creams will not react with the child and all the rest of it." [P13; 6 yr old with egg and peanut allergy]

Parents seemed to suggest that doctors who were more confident with allergy management were easier to talk to and tended to manage their children appropriately.

"And our GP was very good actually and was able to prescribe pro-topics rather than steroids and manage him that way. She was very supportive and made the initial referral". [P1; 5 yr old with eczema and nut allergy]

"*I said, 'Do you think I need to be referred?' Because it's easy to avoid plum…*
and he said, 'Well, I think you ought to be referred to see if he's allergic to any other stoned fruit, so that you're not avoiding it for the rest of his life, when he could actually eat it'." [P8; 4 yr old with plum allergy]

In contrast, parents were very critical of doctors who would not acknowledge their lack of knowledge with regards to managing their child.

"*I think a lot of doctors tend to think that they know everything and [they] don't really know how to deal with situations where they don't have all the knowledge and I don't know whether that's because they feel that there's an expectation from their patients that they should know everything. I think with the first GP I saw, there was some degree of making it up as they went along.*" [P14; 5 yr old with peanut, beans and egg allergy]

Parents sometimes felt that their child as an individual was perhaps disadvantaged due to the clinician's insistence on following set management protocols. This caused frustration and a feeling of helplessness, which one parent described as 'bullying'.

"[The specialist] wouldn't write a letter explaining [my son's] allergies until they made him have a food challenge which infuriated me because he's been in several times with a reaction to milk …. So I had to take him in to witness them – rub milk on, his lips, watch him go into reaction and I'm there thinking, 'Why the hell have you had to do that to my son, just

to write a letter saying, 'Yeah, he's got a dairy allergy?' So in that way, I did feel bullied by the Clinic sometimes" [P22; 15 yr old with dairy, sesame, nut and egg allergy]

ii. Receiving timely and appropriate health care

As with any other medical condition, accessing appropriate healthcare in order to get timely and competent advice is a priority for parents who suspected that their children had allergy. They hope to have fairly easy access to emergency services when their child has a severe reaction, to their general practitioner when they need the child reviewed and a referral to an appropriate specialist when the condition appears complex and an expert opinion is warranted.

In most instances, those who need to engage the help of emergency services felt that these were useful. The 111 service was useful to some parents who needed emergency advice.

"*I thought 111 was helpful, like the woman I spoke to there she was really nice and sort of calmed me down and, 'cos I was quite panicked, and her advice was good in the sense that she sent me to the GP quickly*." [P3; 10 month old with egg allergy]

In some circumstances, although it would have perhaps been more appropriate to contact 999 services, the 111 service was helpful in the management of the child in an acute emergency.

"*so we phoned 111, and went through all of the sort of protocol there of went to the first person, the second person and then the third, and while we were on the phone, and she [the child]was just like completely lifeless and they said, 'Give her the EpiPen now' but despatched an ambulance already, so my husband administered it in her leg, and then we waited for the ambulance to arrive, and by the time they got there –she was actually alright.*." [P17; 3 yr old with peanut allergy]

Some experiences were quite traumatic, with parents caught completely unaware by the reaction.

"..his face started to swell pretty immediately and his voice went, and we had to sit on the car park floor and I gave him his EpiPen and had to shout to somebody to try and phone an ambulance. Well, they all think you're a bit mad, don't they? So nobody – they were just walking past. Eventually, somebody did phone and we had a Fast Response Unit. So that was a very severe reaction." [P22; 15 yr old with dairy, sesame, nut and egg allergy]

Overall, experiences with emergency services were positive. All the parents who accessed these services for their child's allergy felt that they were effectively and efficiently looked after and then referred to the allergy services as appropriate.

Experiences with accessing GP services were more variable. Some parents found that GPs made special provisions for children and therefore accessing appointments was quite straightforward. Others found that getting a same day appointment with their GP can be very difficult and stressful.

"*if you need an urgent appointment, they'll normally ask you a few questions. 'What's it relating to?' type of thing. But you can normally get in within a week*". [P8; 4 yr old with plum allergy]

"*Sometimes you can [make an urgent appointment], sometimes you can't. It all depends on what the problem is. I mean, the receptionist will sometimes say they'll get a doctor to call you back, and the doctor will say 'oh, no, she needs to be seen today, bring her up' or 'no, that can wait till tomorrow, bring her up tomorrow'. And you can always speak to a nurse if you don't wanna wait. The nurse will always speak to you, so… So in that respect it's, it's oka*y." [P19; 20 month old with egg allergy]

"*… trying to get an appointment with them was like near on impossible unless you were prepared to kind of go to their sit and wait surgery which is a bit difficult to do if you've got other children with you*" [P12; 6 yr old with peanut allergy]

"*you have to phone at 8 o'clock in the morning and then they're busy and then by the time you get through, all the appointments are gone and then they say to you, 'Is it an emergency?'*

and you have to tell the secretary what the symptoms are and then they tell the doctor and then the doctor will say, 'That doesn't sound like an emergency'." [P16; 7 month old with milk and egg intolerance]

"– it can sometimes take half-an-hour of phoning to actually get an appointment in the first place, just because when the surgery opens at 8.30 in the morning. But pretty much for any problem –it's almost like a bit of a lottery. You try and phone to get through and it's – I think the switchboard just gets overloaded and it'll just come up with the engaged tone. It's not unusual for me to then look at my phone – because I keep hitting recall, recall, recall, and I've actually tried to call about 120 times. And that's no exaggeration." [P11; 2 yr old with eczema and milk intolerance]

In some instances, although parents were able to access services, they were dissatisfied with the consultation.

"*There were a couple of times when I realised who the GP was going to be and my heart sank a little bit, just because I knew that I was gonna be straight in and straight out. I mean at times we've been in there for 20 or 30 seconds before, 'Oh that's not a problem...see you.' It was that kind of thing. It's no good and you just kinda think, 'Well, somebody's just trying to sort of get through the patients here probably because he's been overbooked or whatever else.' Do you see what I mean?*" [P11; 2 yr old with eczema and milk intolerance]

"– you're very rushed in appointments as well and I don't think you get time to explain fully what it is that you're trying to get across" [P6; one year old with milk allergy]

Some General Practitioners were recognised by parents as having a special interest in allergies or related specialities (e.g. dermatology), which gave them a lot of confidence in GPs ability to manage their children. Parents were very appreciative of the care they obtained from these GPs and sometimes preferred them over clinicians in secondary care.

".. the GP had a specialist interest in kind of dermatology and .. so she was very helpful with eczema support… I think she'd done all she could, and then it was actually she

[who]advised that we looked at getting some allergy testing done so made the referral to the [allergy] clinic." [P1; 5 yr old with eczema and nut allergy]

"*I think the one guy who used to run it when O* was little was – he was something to do with the Eczema Campaign. So when it came to the skin, I was, I was happy to go. As long as the GP has some kind of specialist knowledge about the allergy, then that's fine.*" [P22; 15 yr old with dairy, sesame, nut and egg allergy]

"*I've never felt that the treatment has been poor from the GPs at all, in fact more recently, we were prescribed him an emollient which was fantastic, which was relatively new on the market. So it's always been a positive experience when I go to the GPs. They're fantastic.*" [P18; 11 yr old with sesame allergy]

Referrals to specialists in the NHS are possible only via the General Practitioners or through the Emergency department within the hospital. The process was quite straightforward for a few parents.

"*I saw a GP and explained everything that had happened and she…yeah, just referred us straight on.*" [P3; 10 month old with egg allergy]

"[We] saw the GP or the nurse practitioner, I can't remember now, but they referred me and a few weeks after that we went to see [the specialist nurse]. ... they've been very, very good. I can't fault them at all." [P15; 14 yr old with peanut and macademia allergy]

Securing a referral, however, was a stressful process for some parents. They describe their frustration since their child was not being adequately managed in primary care and yet they faced problems with being referred to a specialist. Parents sometimes had to be quite determined and, occasionally, well planned to secure a referral.

"*I'd sat and refused to leave until I had a referral. I said, 'I don't want to discuss it anymore. I want him referred' because a friend of mine actually told me you can – they can't refuse to refer you. So, I said, 'I'm not leaving now until he gets the referral'*." [P6; one year old with milk allergy]

"*I kind of planned my attack [for a referral]. I was prepared to go in and say, 'Well, I'm not leaving until I get a referral to whatever', but I chose my doctor carefully. So I specifically made an appointment with one of the female doctors at my surgery; She took a look at him and by the time I'd walked out, I didn't just have a referral; I had an appointment.*" [P14; 5 yr old with peanut, beans and egg allergy]

Once a specialist referral was made, most parents expected to wait a few days before being able to actually consult a specialist for the first time. Most NHS hospitals, as per the directive from the department of health, try to ensure that waiting time for first specialist appointment is no more than 18 weeks. While some parents were accepting of this, others were not happy about the wait.

"*Yeah it [the wait] was a while, but I think on the letter it kind of said within 18 weeks or something, they try to get an appointment so it was within the time and it wasn't something that I was desperately [worried about], so I was fine with that.*" [P8; 4 yr old with plum allergy]

"..had it have been something that was recurring frequently I would've been a bit disappointed at the wait time, but I think because I'd already made the decision to cut egg out it was just one of those things." [P19; 20 month old with egg allergy]

"*The appointment letter came through pretty quick, it came through within about three weeks, but when you opened the letter all of a sudden we had to wait another three months to be seen. That was very frustrating*." [P11; 2 yr old with eczema and milk intolerance]

"*I had a quite frustrating experience trying to ring the service, being bounced around from one secretary to another, and then being told that it was the practices fault because they'd used the wrong fax number or something which was a bit frustrating. It was a bit frustrating that some of the back office basics were letting down the service in terms of getting in.*" [P1; 5 yr old with eczema and nut allergy]

Overall, most parents were happy with the care they obtained in specialist centres. They found the consultations thorough and the clinicians very personable. The clinics were described as efficient and effective.

"...'thorough' was a word that definitely came into my head when I was with her [the specialist nurse]..." [P14; 5 yr old with peanut, beans and egg allergy]

"... the food allergy service has always been extremely thorough and supportive." [P18; 11 yr old with sesame allergy]

"*It was brilliant. The, the staff there were fantastic. We arrived, we were seen at our appointment time at the Outpatients*." [P19; 20 month old with egg allergy]

However, some parents had less than satisfactory experiences with secondary centres. This was especially true in the case of a parent who was seen by a general paediatrician at a secondary care hospital prior to being referred to an allergy specialist.

"*I wasn't overly satisfied. On a personal level, the people there were very nice but in terms of the service, no - not overly satisfied really*." [P14; 5 yr old with peanut, beans and egg allergy]

The reaction to follow-up care was mixed. While some found them useful, others were critical. They questioned the usefulness of short consultations and also the organisation of follow-up clinics.

"[the follow up] was very useful because up until a couple of weeks back [my daughter] wouldn't entertain eating a nut. So now she is eating other nuts, and she is absolutely fine. [The specialist nurses] at the hospital, you know, they were the catalyst to push her to do that. So from that point of view, it has been very useful" [P15; 14 yr old with peanut and macademia allergy]

"*.. we only really get about ten minutes in the appointment and .. so it's not kind of an in-depth appointment really, it just I feel like there should be a little bit more ;.. it's the worry of knowing that the reaction is so severe, that anaphylactic shock that's really scary to me so I*

feel like having a ten minute appointment once a year isn't really enough." [P12; 6 yr old with peanut allergy]

"*When we go to Clinic now, we'll go and see [the nurse] and they'll then do a skin prick test which just seems to get worse every time and then there's not really anything else they can do, is there? So you go in and you do get to a point where you think, 'We know he's still allergic. ...They just do the skin prick test,– the size of the reaction seems to get bigger and then they'll just go, 'Carry on avoiding'*" [P22; 15 yr old with dairy, sesame, nut and egg allergy]

iii. Clinician seen in hospital

In both of the secondary care centres chosen for recruitment in this study, most of the consultations are carried out by specialist nurses trained in allergy. A majority of the parents that were interviewed were unaware of this and had, in fact, presumed that they had been seen by a doctor (although they were actually reviewed by the specialist nurse).

"*I thought she [the specialist nurse] was a doctor."* [P6; one year old with milk allergy] and [P3; 10 month old with egg allergy]

A few parents had been seen the specialist nurses over a few years and had developed a good relationship with them over time. They trusted their experience, knowledge and competence and were happy with the current clinic set-up.

".. I think she's probably had more specialist training in that area than some of the doctors have. She very experienced and I trust her one hundred per cent." [P20; 10 yr old with peanut, cat and dog allergy]

Some suggested that nurses are more approachable than doctors and hence the consultations tended to be more informal whilst still being effective.

"*It's almost a bit more laid back – or maybe it seems more informal; in which case, it's easy to, you know – I find it very easy to explain to [the nurse] the difficulty that I have being*

a parent of boys with food allergies and I think they also feel like they can tell her things as well." [P18; 11 yr old with sesame allergy]

Some parents felt that specialist nurses were perhaps better informed than doctors since they are focused on a specific disease area whereas doctors may not have a lot of in-depth knowledge in the field.

"*I've got much more faith, at the moment, in nurses than I have with doctors. I just think they don't seem to look down their noses as, 'I'm a GP. I know everything. You know nothing' which is how I'd been treated for so long. They [Nurses] are not under as much pressure and the minute I walked in, I thought, 'No, they are purely here for him [my son]'. You know,– it wasn't like a conveyor belt; if you've got a ten minute appointment, on you go. It was however long it took was fine and we were the last ones of the day, so it didn't matter how long it took*." [P6; one year old with milk allergy]

"*To be honest, I think sometimes a specialist nurse knows more than a doctor that is with too many areas. And, and I think because they, they know more about specific things, if you wanted to ask, about research or things like that, I think they, Nurse Specialist would know more than the paediatrician would*." [P9; 8 month old with multiple food intolerances]

"*to be honest with you, they tell you at the beginning so initially, I was a bit surprised to begin with but when she then started talking about everything that she'd been doing - I just felt confident that she was the right person to deal with it [the allergies]. So she just seemed really on the ball, to be honest, so it didn't worry me.*" [P17; 3 yr old with peanut allergy]

Whilst most parents did not express a preference for being seen by doctors in the specialist clinics, some felt that there should be a doctor available as 'back-up' in case of complex conditions where the nurse may be overwhelmed.

"*So I think, [with] a more sort of knowledgeable, nursing type individual, -we would actually feel quite good about that. So as long as all the mechanism's there to say okay, well, in the first instance there's a specialist nurse to talk to but if there's still a possibility…,*

like a backup, there's a way of referring back to a consultant again. I think that's potentially something that can work quite well." [P11; 2 yr old with eczema and milk intolerance]

"*I think it's always nice to see a consultant and have more tests and what have you [if the child was having more reactions]. If it's an ongoing daily battle then I think the more help you have the better you're advised, really, aren't you*?" [P15; 14 yr old with peanut and macademia allergy]

However, a few parents explicitly preferred seeing a doctor and were disappointed when this was not possible.

".. we didn't see the consultant, which I must admit is what I'd expected, given that the GP had referred us... But I guess while we've seen the nurses and not the consultant there's perhaps that nagging doubt that if we'd seen the consultant would the advice have been slightly different." [P1; 5 yr old with eczema and nut allergy]

iv. Support with allergy management

Parents were generally pleased with the care they got from hospitals. Often, the allergy clinics put them in touch with other services such as dermatology or dietetic services so that the parents can be given adequate advice regarding management of their children. Sometimes, such referrals take a long time to materialise and this can cause enormous distress to parents. This is especially true when the child has been quite unwell – parents may be left without any support or information during the period between initial assessment at the hospital and the follow up appointment.

"*It was all fuss, fuss, fuss, big, big, big problems in a hospital bed for weeks with all these tubes and things and then it was like, 'Off you go and see what happens'. It just – I just don't understand*." [P16; 7 month old with milk and egg intolerance]

Sometimes, it was not possible to obtain co-ordinated care between various specialists, even when this was perhaps warranted.

"..he has an eye condition – they call it Giant Capillary Conjunctivitis which is another allergy condition... but I mean the Allergy Clinic doesn't deal with that kind of allergy. It would only deal with food allergies, so .. for his eyes, he was under another consultant.. So [the ophthalmologist] -all he could do is just say, 'We're going to deal with what's put in front of us'. Whereas obviously, there's something there that's triggering this off .... It was an allergy, so – but he didn't understand allergies" [P22; 15 yr old with dairy, sesame, nut and egg allergy]

Children who have suffered serious reactions as well as their parents appear to manifest a lot of anxiety and isolation that is perhaps not being directly addressed by the healthcare system.

"..that asthma [attack] then stopped him – he had to stop all sort of sporty activity for about a month because he was struggling to get his breath and then, after that, he struggled to get back into anything sporty and now, he doesn't – he's not into sport whatsoever. So it did [have] a big knock-on effect to his life. Whether it like scares him, I don't know but – he stopped his cubs, he stopped his gym, he stopped his trampolining." [P22; 15 yr old with dairy, sesame, nut and egg allergy]

Some parents try to 'get on with it', whilst acknowledging the stress associated with managing allergies in their child.

"... actually having children with food allergies is really stressful, but you get on with it, don't you? Because you have to. And you don't realise just the impact it has until they've grown out of it and all of a sudden, you think, 'Oh, phew! Thank goodness'." [P18; 11 yr old with sesame allergy]

Some parents feel that such stress should be more openly acknowledged and managed by the clinicians.

"*Is [counselling] offered to children and parents that have had that life-threatening ordeal which is terrifying?! Is that ever followed up? Does anyone ever actually follow them up and*

give them a phone call and say 'would you like someone to talk to'?" [P20; 10 yr old with peanut, cat and dog allergy]

v. Issues with information

As with any other childhood condition, parents greatly valued reliable information regarding their child's allergies. Information was generally obtained from the clinicians, through peer groups or from the internet. Clinics were sometimes able to provide information that parents found very useful.

"... they did have a Nutritionist who then told me these things, that were available on the market, which I would never have known about and .. a lot of things we then got on prescription,– I mean we were wheat free as well." [P22; 15 yr old with dairy, sesame, nut and egg allergy]

"*Since seeing [the specialist nurse], I came home with a cookery book and we've made him chocolate cake that the whole family ate.*" [P6; one yr old with milk allergy]

"*She [the specialist nurse] was really good, gave us a lot of information and explained what to do and, she suggested that we try her with very well cooked egg, because she [the child] had had it before, and we were both pleased.."* [P3; 10 month old with egg allergy]

However, some parents had a period between seeing their GP (or A&E) and being seen by the specialist when they experienced an information hiatus.

".. we didn't leave the GPs or the hospital (A&E) with anything other than sort of what we'd been told verbally, which was quite limited really." [P3; 10 month old with egg allergy]

Most parents obtained information from peers (fellow parents) by having informal conversations with them. This provided them with practical tips and also a sense of 'not being alone'.

"*I have a good friend whose son is very allergic to milk and eggs and I spoke to her and she said, 'Oh, maybe he's allergic to milk as well'. So I then rubbed a bit of milk on his arm and sure enough, he came up in hives*" [P18; 11 yr old with sesame allergy]

"*I go to a group, a little meet up with other mums who are also weaning and trying different diets but you compare notes, you know. I run into people here and there and have conversations about it.*" [P16; 7 month old with milk and egg intolerance]

Lack of such support can lead to a feeling of isolation and increased anxiety.

"... primarily, I was the only one [with this problem]. I only knew that other mum for a short time and then she moved away I was the only one whose child was going through this, so [having a local parent support group] might have been quite a good idea." [P14; 5 yr old with peanut, beans and egg allergy]

Many parents also used the internet to obtain information regarding allergies. Accessing peer groups on the internet was particularly popular (e.g. mumsnet, netmums) as these seemed to provided emotional as well as practical support to most of the mothers interviewed. The accessibility and anonymity of these forums as well as the empathy that these scenarios generated from other users was particularly comforting to our interviewees.

"*NetMums is a great one because it's one of them you can put the daftest question regarding a child that if you think it's stupid and there's always a mum that somebody's been through it and, you know, they can give you advice…"*[P6; 1 yr old with milk allergy]

"... I've gone on Facebook and I've joined [a group] for people .. that have got children with allergies and I've found that quite helpful, that people put things on like 'ooh, I've just found out this contains egg' or 'I've just found this product and this doesn't contain egg and my daughter loves it' and so I've found that really helpful." [P19; 20 month old with egg allergy]

Whilst parents appreciated the support provided by internet, most also expressed some reservations about relying solely on such information. They recognised that the information

obtained was not always accurate and can sometimes be misleading. Parents do prefer obtaining information from reliable websites (eg. NHS direct). However, some found these inadequate and disappointing.

"*Sometimes (my husband) will say, 'oh no! Don't look on the internet' because you know I can be a bit of a, oh my God this sounds like he has this or that or the other*" [P7; 3 1/2 yr old with eczema and asthma]

"*To be honest there's more advice outside the NHS website– at least in my experience - when it comes to allergies and things like that. I mean generally the NHS website is brilliant, especially for general sort of issues on kids and things. They do give you a very unbiased – a well-balanced bit of advice. But when it came to allergies and intolerances it was next to useless really.*" [P11; 2 yr old with eczema and milk intolerance]

vi. Suggestions for improvement

Parents generally appreciated the services that they received. Some were very happy with the pathway overall and did not envisage the need for improvements.

"… if everything continues the way that it's gone, then that's spot on." [P17; 3 yr old with peanut allergy]

However, most parents felt that there was room for improvement. Access to GPs, referral practices, secondary care appointments (including follow ups) could be better. Information provision could also be improved and follow up visits could be made more informative.

Parents were critical of the premises used by one centre (Birmingham Heartlands Hospital) for their clinic.

" It's a very nice building but it's just not fit for purpose. I mean it's convenient to get to but they haven't got any parking. It's a very tight set of doors – it's very old buildings. The first thing you're greeted with is a set of stairs and then some very small tight doors and then another set of stairs. We had to struggle up the stairs. We had to carry the pushchair up the stairs." [P11; 2 yr old with eczema and milk intolerance]

Some parents felt that knowledge base of GPs with regards to allergies should improve, especially because of their role as gate keepers into the system.

"...better equipped GPs, in terms of that sort of first response; having a bit more advice to give knowledge wise, and a stronger mechanism there to sort of refer onto specialists." [P11; 2 yr old with eczema and milk intolerance]

Access to secondary care (in terms of obtaining referrals) and also the inflexibility of appointments were also sticking points for some parents.

"*our experience was that wasn't great in terms of the route; we didn't have any control over the appointment as family, we kind of got told this is the date you will go. We didn't have a lot of choice in terms of when the appointment was which I could see would be difficult for other families potentially in terms of access*." [P1; 5 yr old with eczema and nut allergy]

"*Before you even get to your appointment because there's quite a wait for your appointment at the allergy clinic, it would be useful to be given information from the GP so that you know what to expect and a bit about what to avoid in the meantime and things like that.*." [P12; 6 yr old with peanut allergy]

"... the waiting times for the appointments should not be so long, because we've been waiting months for the appointment." [P9; 8 month old with multiple food intolerances]

Parents also felt that there needs to a facility that acknowledges and addresses the anxiety that is brought on by allergies. Some felt that the psychological trauma brought on by allergies is often ignored.

"*One of the best things that they could do is give [the parents] somebody that they can speak to without feeling they were taking up their time. Their sole purpose would be to [let you] unload your baggage on them."* [P22; 15 yr old with dairy, sesame, nut and egg allergy]

Another issue that was brought up was the lack of adult allergy clinics for grown up children, especially in Shrewsbury region.

"*I mean especially now [my son] is older, I don't even know where we go. We haven't got anywhere to go. There's no Adult Allergy Clinic*" [P22; 15 yr old with dairy, sesame, nut and egg allergy]

"*It's just a shame it'll all finish in the next 18 months. That's a real shame because they're still youngsters and teenagers can get complacent and it's good to have that reminder and that check-up, you know.*" [P15; 14 yr old with peanut and macademia allergy]

5.4.4 Theme 4: Effect of allergy on daily living

Effect on the family

A diagnosis of allergy in a child has implications for the life style of all the members within the family. One of the issues that parents found difficult was the fact that it was sometimes difficult to convince family members about the seriousness of a condition when the child looked quite well otherwise.

"*My nan, she's 92. She said, 'Allergies? Never had allergies in my day'."* [P6; one yr old with milk allergy]

"*I mean they're not worried like I am. I think it's slightly different being a parent. I'm probably more worried than I should be rationally. They don't seem to have that sort of fear factor .."* [P18; 11 yr old with sesame allergy]

"*my father-in-law loves nuts and he eats them all the time and when he's eating nuts, I'm wiping around after him – 'What have you touched?' He's like, 'Don't worry about it. She'll be fine' – this, that and the other*" [P17; 3 yr old with peanut allergy]

In most cases, siblings- even those who are quite young themselves, assumed a lot of responsibility to ensure that children with allergy were safe.

"*I mean, the girls are very, very aware of his allergies. It's like my little, littlest one had a bowl of chocolate cereal and she dropped it and she went, 'Oh mummy, pick T up quick while I get them all'. So, they know not to feed him. They check everything. They know not to sit*

there and give him something. If you ask them why, they'll say, 'Because it makes him very sick'." [P6; one yr old with milk allergy]

Relationships with friends and family

Allergy in children can cause a lot of anxiety within families. Children who seem otherwise well can become very ill within a few minutes if exposed to substances that they are allergic to. This anxiety is especially pronounced when children have food allergies and when they are at risk of life threatening reactions such as anaphylaxis. Parents are often worried about delegating the care of their child to others, including family. Sometimes elaborate arrangements have to be made to ensure that parents can leave their children in someone else's care for a few hours.

"I've written a really long -probably too long- kind of list of everything that she's allowed to have and not have and what she likes and I – you know, prepare all the food the night before and it's very pedantic, isn't it? To make sure, you know, that everything's right for her." [P16; 7 month old with milk and egg intolerance]

" *Well, you know, most of my others, by the time they were a year old, they'd been and stayed at their auntie's for the night but with him– I'm still quite anxious...*" [P6; one year old with milk allergy]

The implications could extend beyond the safety of the child, in some cases.

"*my fiancé found it quite difficult because he'd never seen [my son] have a reaction, he just kind of didn't believe the things that I said; It got to a point where, you know, we never had dairy in the house but he insisted on having it. So that's broke – that has helped break our relationship up ..."* [P22; 15 yr old with dairy, sesame, nut and egg allergy]

Childcare arrangements

Parents need to ensure that everyone who looks after their children is aware of the risks and management of symptoms, when they arise.

"*He has had a couple of [episodes] where he's been sick when he's had, he's eaten something it's reacted that badly with hives but I think you know how to manage it, school know how to manage it and he goes to kind of an after school club as well. So everybody knows, everybody's got Piriton. Everybody knows if it's really serious it's 999, everyone's got inhalers and things like that - so I think that side of it is quite well managed really."* [P1; 5 yr old with eczema and nut allergy]

" I had advised the child-minder of what had happened, and just said that I will obviously provide all her food but [she] just needs to be careful what [she is] giving her, really, and there's certain biscuits that [the child] can have, there's certain biscuits that she can't.." [P19; 20 month old with egg allergy]

Schooling

Parents were able to choose nurseries and child minders who were sympathetic to the health issues of the child and were able to accommodate these whilst providing care. However, in some instances, primary schools were found less accommodating. This caused a lot of stress and had significant implications for the child and the family.

"*I think I've noticed a big difference going from nursery to school, I think nursery perhaps had more time to put the cream on and do it for him. I think at school there's more of an emphasis on [the child] doing it himself, which he's sometimes a bit reluctant to do"* [P1; 5 yr old with eczema and nut allergy]

"*We didn't have difficulties until we started to try and get him into Primary School and then you found that people were not that forthcoming or happy to change anything in order for him to be included in all the activities. Yeah, we ended up picking a school that wasn't even in our catchment area because they were the ones who were, you know, more than willing to [take care of him]*" [P22; 15 yr old with dairy, sesame, nut and egg allergy]

Some schools are, however, very supportive and ensure that appropriate steps are taken to keep the child safe. This is, obviously, very reassuring for the parents.

"*And the school, the, the school she's at is very, very thorough about it. They've got a nut-free policy at school. And if they have cake sales everything has to be labelled correctly and, you know, they are very, very good because - and I think there's another girl in her class who's allergic to all nuts so they are super, super careful*" [P15; 14 yr old with peanut and macademia allergy]

Self management

As the children themselves grew older, they start to take responsibility for the condition and shoulder the burden of management. Parents were cautiously happy about this since it is quite difficult to maintain control over the children's life and diet as they grow up.

"*She's very good, she just sort of gets on with it really and you know, she's, if she's going to a friend's house who's got a cat and a dog, she'll just either have had anti-histamine before she goes or has you know, things with her to deal with it, yeah a little bit like me really, it's just sort of, it's just part of life and you just get on with it.*" [P21; 16 yr old with hay fever]

"*He'll go into town, he'll manage – he knows what he can eat – I mean, it's a lot easier now than it ever used to be, believe me. I think he's man enough now to say, 'Can you swap the chopping board' and he'll always have a bite and check that he doesn't get a tingle and then he'll go ahead and eat it*" [P22; 15 yr old with dairy, sesame, nut and egg allergy]

"*Yeah he's really good I mean he's more vigilant than most adults because if he's not sure about something he won't have it, I think he's scared himself really, he doesn't want to have to use the epipen because he knows it's a needle.*" [P12; 6 yr old with peanut allergy]

Nevertheless, delegating the entire responsibility of allergy on to the child can be very stressful for the parents, even if the child is 'old enough' to take care of themselves. Parents find themselves torn between the need to keep their child safe, but also to avoid cosseting them and impair their growth into confident adults.

"*Well, he hasn't been away without me so far. He's always got me in tow but I mean for holidays but there'll come a point where he goes, you know, with friends . I mean he is very sensible and grown up but there are always times, aren't there, when we make mistakes or we're just not sure? So it's that independence but it's like anything, isn't it? I suppose all parents worry about their children making their way into the world because there's all sorts of things that potentially could happen. This is just one of many, isn't it?*" [P18; 11 yr old with sesame allergy]

"*She's got to lead her life and I can't wrap her up in cotton wool. You know, they go on school trips. So she's, she's got to take a bit of responsibility for herself and she is, she is very good at that and she knows if she's not sure she won't, she won't eat it, whatever's in question.*" [P15; 14 yr old with peanut and macademia allergy]

Social aspects

Allergy affects other aspects of a family's life. Eating out as a family can become a difficult task, which many parents choose to avoid.

"... when you go to a restaurant, she loves like spaghetti bolognaise and macaroni cheese and that sort of stuff which you always find on a children's menu, and when you ask them if it contains egg 'Ooh, we don't know; we buy it in packets'. So she obviously can't have that but then if my son wants spaghetti bolognaise and she can't have it then that poses a problem because she can't have pasta ..." [P19; 20 month old with egg allergy]

Social events such as birthdays, family gatherings could get stressful.

"[Sometimes] you can see other people thinking, 'Well, just because he's got an allergy, it doesn't mean that the others should miss out,' type of thing." [P8; 4 yr old with plum allergy]

"*if it's someone's birthday or something he generally can't have the birthday cake ...It does bother him a little bit because I mean like if there's a chocolate birthday cake he's like 'oh I can never have chocolate birthday cake' so I think that upsets him..*" [P12; 6 yr old with peanut allergy]

Food labelling

Other activities, such as shopping, that are normally routine (and perhaps mundane) for most families become very difficult for some of these parents. They found that 'quick trips ' to the shops were not easy and picking things 'off the shelves' for their children can be unsafe.

"*when I could tell that he wasn't having dairy, it took...ooh, about an hour to pick up six or seven jars of baby food because I had to read every one of them and the security guard started to follow me round the store because I'm picking up, looking and putting everything back. So, I sort of turned around and explained to him and I thought, 'This is just the first of many*'" [P6; one yr old with milk allergy]

"*But it was a case of reading the labels, being an avid label reader. Your shopping took a bit longer because you had to read the fine print and pay attention, you know, rather than just throwing it in the trolley.*" [P20; 10 yr old with peanut, cat and dog allergy]

"*I'm quite fastidious now. Anything that we buy that's new, I read the label, and read the label, and the read the label again.*" [P18; 11 yr old with sesame allergy]

Parents find the different labels such as 'may contain', ' packaged/ manufactured in a factory with', 'traces of' etc quite confusing. While some avoid products with any mention of the allergens, others choose to avoid only those products that explictly state that the allergen is present. There was no clear understanding of what the different labels meant and what could be avoided to keep the child safe.

"*if it says, 'May contain peanuts,' or, 'traces of peanuts or macadamia nuts,' then I don't buy it. If it says, 'It may contain traces of nuts,' generally I do buy it because everything says that.*" [P15; 14 yr old with peanut and macademia allergy]

"*some of them do say 'made in a factory that uses egg products', so I tend to stay away from that ; but it's just when it says on the side 'may contain egg'. You know, one tin might and one tin might not? It's, that's what I find a bit confusing.*" [P19; 20 month old with egg allergy]

"*Yeah a lot of it is hard because you don't know if it's just the company trying to cover their back or is it genuine user risk... you're not sure.*" [P12; 6 yr old with peanut allergy]

Cost

Unlike gluten free diet for coeliac disease sufferers, 'free-from' foods for allergies cannot be obtained on prescriptions. Hence in some instances- especially dairy allergy- allergies had a significant impact on household finances.

"*I mean the cost of soya milk alone is a lot higher. But you don't eat just to sustain yourself, we've got taste buds and we eat to enjoy our food as well, so there's an aesthetic element to it as well. But it's not just that; it's the fact that you've got to double up on everything that you buy then as well. So again when we were making pizzas and things like that, buying extra pizza bases that didn't have any dairy products in them or any tomato or any of that kind of thing.*" [P11; 2 yr old with eczema and milk intolerance]

"... it's an expensive range. It's silly what you pay, you know, for non-dairy food and it's – there's more children that are coming up with allergies. It's not fair." [P6; one yr old with milk allergy]

5.5 DISCUSSION

5.5.1 Principal findings

This study shows that parents experience significant barriers in accessing primary and secondary care allergy services for their children. Access to primary care was difficult in some cases, with others reporting a worsening over time. Many parents found getting same day appointments with GPs very difficult and given that they were anxious regarding their child's health, they describe helplessness and frustration in their inability to access timely medical advice. Referrals to secondary care were also identified as being a problem, in some cases the parents had to wait many months and resort to extraordinary practices (e.g. refusing to leave the GP surgery) before referrals could be made. Experiences with secondary care were generally positive, although the long waiting times and the quality of follow up appointments were criticised by some parents.

Parents described a variety of presenting symptoms of allergy in their child. These varied from mild rash to a serious anaphylactic episode. In some instances, the diagnosis was quite apparent at the outset whereas in other cases, the culprit agent was difficult to identify and took repeated physician appointments. Where there was some family history or other experience with allergies, parents found themselves a little more confident about managing these in their children.

In any case, what parents appeared to value highly in the management of allergies was the acknowledgement from others, specifically physicians, that they are indeed justified in their concerns for their child's health. Even in situations where the physician was not able to offer a diagnosis, parents greatly appreciated being listened to and taken seriously. As a consequence, they expected to be referred to a specialist if the GP is unable to help. Referral practices, however, are quite variable all across the region. The reasons for this are not fully understood, but studies suggest that income deprivation, sex and age may influence referral rates for certain conditions[171]. Even when referrals have been made, the waiting time to see a specialist in allergy is usually quite long. Depending upon the seriousness of the allergy and the severity of ongoing symptoms, whereas some parents were upset about the waiting time, others were more tolerant.

Access to reliable and appropriate information was an issue which many parents found wanting. Many do try to access online information, but are wary about reliability of most websites. Many of the mothers interviewed found peer support websites (such as netmums, mumsnet) very useful, mainly for the advice but partly for the empathy that they get from the other users. A few were unhappy about the lack of information from reliable sources (such as the NHS information website) regarding allergies. Although there are some good websites offering advice on allergies (RCPCH, Allergy UK, anaphylaxis campaign)- these are clearly not well publicised and GPs ,and consequently parents, remain unaware of their existence. Improving GP knowledge of these websites is relatively easy and can provide considerable dividends in the management of these children.

In general, parents rely heavily on others such as family members, child minders, nursery staff, school personnel to help them look after their children. When children have allergies, particularly food allergies, parents find it stressful to delegate childcare to others. This is often because children, who otherwise look well, can become seriously unwell if exposed to the culprit agents or foods. Parents are worried that others may not take the allergies as seriously as they should and may subject their children to unnecessary risks. Easily accessible, reliable information may be helpful in providing families with some support in this regard.

Shopping for 'free from' foods and problems with labelling of food substances can seriously blight the quality of life of these families. Parents are unable to just ' pick foods off the shelves' and have to spend a lot of time reading through small print on the labels. Whilst parents have welcomed the recent improvements in labelling across the UK [172], shopping continues to be difficult - sometimes compounded by the additional cost of allergen free foods and their impact on the family budget. Apps such as food maestro® can also be helpful and could be offered to parents/ patients with food allergy [173].

The range of narratives in this study was broad and depended, to some extent, on the geographical area of residence, the age of the child, pre-existing allergy knowledge of the parents (if any), the nature of the child's allergy symptoms. These could be considered as 'fixed factors' in service delivery - attributes that cannot be altered. However, parents did allude to other issues that were directly related to the quality of service received. These included poor access to GP services, poor knowledge of GPs with regards to allergy, issue with procuring referrals to secondary care, prolonged waiting periods to see a specialist even after a referral has been made, poor information access, need for psychological support in some cases and lack of transition to adult allergy services in some areas. Any plans for service re-organisation and service improvements in allergy within the WM area should, therefore, take into account these factors in order to be effective.

5.5.2 Strengths and limitations of this study

This is the first in-depth study into parent experiences with allergy services in the UK. We interviewed parents attending two specialist allergy centres within the WM which allowed us to capture a range of experiences, since these parents had accessed both primary and secondary care services for their children. The specialist clinics were geographically distant (about 50 miles apart) and therefore there was no overlap of services (in terms of GP practices and supporting services such as dieticians).

The sample size for this study is much smaller than that of quantitative studies. This is, however, not a limitation as such and is in keeping with other published qualitative research. The depth of information obtained from this study cannot be obtained from a quantitative study (e.g. a questionnaire study) using a large patient sample.

One of the limitations of this study could be the limited number of children with specific allergies (see table 1). Interviewing more parents of children with milder allergies (such as hayfever) as well as those with serious allergies (e.g. with history of anaphylaxis) could give us further information regarding the differences in experiences in these scenarios. However, the purpose of these interviews was not to evaluate the service pathways for specific allergies but to understand parent experiences with general NHS paediatric allergy services in the WM and hence an unselected population was preferred.

Almost all of the children included in this study were reviewed by specialist nurses. Although the experiences in specialist clinic were mainly positive, it is possible that there may have been variations in experiences if more parents had been seen by consultant allergists or immunologists. In addition, the experiences of parents attending clinics run by general paediatricians not formally trained in allergy which are likely to be important in the WM (since such clinics constitute a majority of secondary care provided in the region) were not explored in this study.

Another potential limitation was the under-representation of fathers in our study. The recruitment process was modified after the interim analyses to attempt to recruit more fathers

but this was not possible. Although there may be differences in how parents perceive allergies[174] it is not clear whether interviewing more fathers could have changed the findings in this study.

As with most other qualitative studies, the data obtained are valid only to the population surveyed (i.e. parents in the WM whose children suffer with allergies). The results are not generalisable to other areas in the UK or, indeed, to other countries.

5.5.3 Strengths and limitations in relation to other studies

A previous report into allergy services has reported anecdotes relating to service pathways in the UK. These were comments made by callers to a help-line rather than those related to in-depth interviews. This is the first study to explore parent or patient experiences with allergy pathways.

Other studies have been published which report children's experiences relating to health care services in general [175]; pathways of care related to specific conditions such as diabetes [176], children with special health needs [177]; healthcare access for a selected group of people – e.g. Elders in rural West Virginia [178]. However, none of these studies have evaluated experiences related to complete service pathways (i.e., primary and secondary care, supporting services) for a particular condition.

5.5.4 Plans for further research

As previously discussed, attributes obtained from this study will form the basis for a quantitative study (a discrete choice experiment) which aims to understand parent preferences for paediatric allergy services in the WM region.

Interviewees in this study were limited to those to attended specialist clinics run by personnel specifically trained in allergy. However, a majority of paediatric allergy services in the WM and other regions of the UK are provided by non-specialists (e.g. paediatricians or nurses not trained in allergy).Interviewing parents who attend non-specialist secondary care clinics can potentially add to the results of this study and will be considered in the future.

5.6 CONCLUSIONS

Paediatric allergy services in the WM region are disparate. Parents experience difficulties in accessing primary and secondary care services and also obtaining timely and appropriate information regarding their child's allergies. Whilst some GPs were described as competent and sympathetic, others were found to lack knowledge regarding allergies- causing parents a lot of distress. Experiences with secondary care were mostly positive although there were some issues with the usefulness of follow up clinics in some cases, lack of adult allergy clinics and also issues with referral to other specialists, where needed. Some of the participants felt that extra services such as counseling for parents whose children have severe allergies, better organisation of parent peer groups should be facilitated by the NHS.

5.7 REFLECTION

Although it would be preferable (in any research) to ensure that the researcher has no influence on the results, this is not possible in qualitative research. The issue, therefore, is what degree of researcher influence is acceptable – currently there is no consensus regarding this issue[179].

In this study, the principal researcher (LD) was the interviewer and this could have influenced the conduct of the interviews, the analysis and the interpretation. The researcher was unlikely to have been completely objective given that she had many things in common with the interviewees (who were mostly working women with young children). In addition, LD is a clinician with expertise in allergies and her knowledge in this disease area would have definitely influenced this project. For example, it was difficult not to sound surprised when one of the parents suggested during the interview that her GP advised her to feed her child peanuts when the clinical history suggested that she was very likely to be allergic to them. The surprise in the interviewer's tone may have modified the mother's description of that event and perhaps changed the tone of the rest of the interview.

Whilst there may be no feasible method of avoiding such influences on the study, it is important for the influences to be made explicit in order that the results can be interpreted in the given unique context [180]. Overall, every effort has been made to ensure that the context in which the quotes are presented is a true reflection of the (interviewer's interpretation of the) interviewee's intent.

Whereas it was important to understand what parents experienced in the WM when accessing allergy services for their children, more important for service planning would be to find out their preferences for these pathways. A quantitative survey of parents across the WM was therefore planned to understand what parents preferred while attending specialist services for allergy. The details of this study are explained in the next chapter.

6 PARENT PREFERENCES FOR SPECIALIST ALLERGY SERVICES IN THE WEST MIDLANDS

In the previous chapter, a qualitative study aimed at understanding the experiences of parents accessing NHS allergy services for their children in the West Midlands (WM) region was discussed. Parents faced barriers accessing services and, on occasions, felt that they had received a sub optimal service. They also highlighted the impact their child's allergy on many aspects of daily living. The service pathways related issues raised by parents (See 5.4.3) were used to further plan a quantitative study known as a discrete choice experiment (DCE) aimed at understanding preferences of parents in the WM for specialist paediatric allergy services. After briefly introducing stated preference methods and choice experiments, this chapter will discuss the design of the study, pilot studies undertaken, details of analyses and results of the DCE followed by a discussion and conclusions.

6.1.1 A few definitions

Preferences

The Oxford English dictionary defines preference as a 'greater liking for one alternative over another'. In economic terms, preference is the ordering of alternatives based on their relative utility, resulting in either hypothetical or real world choices [181].

Utility

Utility in economics is a measurement of satisfaction or happiness obtained by consuming a given product or good [182]. Although the utility derived from goods is subjective and varies from a given individual to another, consumer choice theory dictates that all consumers necessarily act rationally and make decisions aimed at maximizing utility [182].

Opportunity costs

This is defined as the benefit forgone by choosing to invest resources on the given good or service rather than the next best alternative [182]. For example, the opportunity cost of investing in a new car may be a family holiday. A 'trade-off' is a similar concept and refers to giving up on a particular good or service in favour of another.

6.2 BACKGROUND

As the discussions on healthcare broaden and the public get more interested in their health services, the pitfalls of focusing exclusively on health related outcomes have become more apparent [183, 184]. Quality of life instruments such as the EQ-5D, it is argued, measure health benefits almost to the exclusion of all other outcomes [185, 186]. Yet there are data to suggest that non-health outcomes make a substantial difference to the health and well-being of individuals and their families. For example, providing advanced end of life planning improved mental health outcomes for families after the death of their loved ones [187]; distance from a hospital can have substantial impacts on families with children suffering chronic medical conditions [188]; negative staff attitude towards individuals abusing drugs can result in suboptimal care [189]. Nevertheless, none of these outcomes can be captured adequately with the use of generic quality of life instruments. Indeed, the emphasis on health

related outcomes can narrow the focus of clinicians providing healthcare resulting in poor patient experience [190].

Recently, there has been interest in considering broader patient views regarding health outcomes as well as health care related experiences [191]. Understanding patient preferences for health care can improve the efficacy and efficiency of health pathways. Shared decision making (SDM), an initiative championed by the UK government for better NHS care, aims to involve patients not only in decisions regarding their own health but also in commissioning and designing of healthcare [192].Such involvement has been shown to improve experiences with health pathways as well as outcomes for patients. In addition, SDM can help reduce variations in quality of services and thus contribute significantly to commissioning [192]. Indeed, the idea of involving the public in health policy has been gaining momentum in the UK and elsewhere [193]. Studies have shown that the public want to be consulted about planning health services [194].

Allergy services in the UK, as discussed in Chapter 2, are inadequate and in need of improvement. There have been suggestions that preferences of local population should be considered in allergy service planning [3]. This will help improve public involvement in health services as well as increase accountability of commissioners and health care practitioners [191].There are various methods by which public involvement in service planning can be achieved. Preference elicitation is one such technique which is widely used [195].The methods used to understand preferences are rooted in economic theory and have been successfully used in areas such as transport, environment planning , market research as well as health [196]. Some of the preference elicitation methods are discussed below.

6.2.1 Preference elicitation methods

Eliciting individual preferences to inform health policy is firmly rooted in welfare economics [197]. Preference elicitation methods can be broadly classified into two types- those that elicit revealed preferences and those that capture stated preferences [198].

Revealed preferences [RP] can be understood by examining actual consumer behaviour in real-life market scenarios [199]. For example, a person weighs up various factors before choosing a particular shampoo from a supermarket shelf. These characteristics or 'attributes' may include brand, cost, colour, advertising, smell or a host of other relevant features. By choosing a particular product or good from amongst a raft of similar products, the consumer has expressed or 'revealed' their preference. By studying the revealed preferences of individuals over a period, it will be possible to understand the attributes that dominate their choices [196].

Revealed preference [RP] data cannot be used for valuation of health care programs or pathways since open markets do not generally exist in the health sector [200, 201]. Another issue is that RP does not allow evaluation of services that the individuals have never faced [201]. Stated preference [SP] experiments (discussed below) are therefore preferred in the elicitation of health and health care related preference data [196].

SP experiments usually involve providing respondents with hypothetical alternatives which differ on the basis of certain characteristics or attributes [200]. The respondent is expected to choose an alternative that maximises her utility considering all attributes and by trading-off between them rationally. The choices they have made can be used to understand the value placed on individual attributes and the importance of one attribute relative to another [200, 202]. The biggest criticism of SP is that the preferences may not have any consequence beyond the hypothetical- i.e., the individual is not necessarily committed to the choice and may choose differently when faced with a real life situation [200]. However, the imbalance of information between the providers and consumers in the health care sector results in patterns of consumption that are not based solely on consumer preferences [201]. In addition, SP methods are uniquely suited to help understand preferences of individuals for goods and services before investments can be made and are being used increasingly in health care.

There are various types of direct SP elicitation methods described in the literature. Broadly, SP methods fall into two categories based on the outputs generated, those that elicit ordinal preferences and those in which the preferences are cardinal [200] (See Fig.6-1).

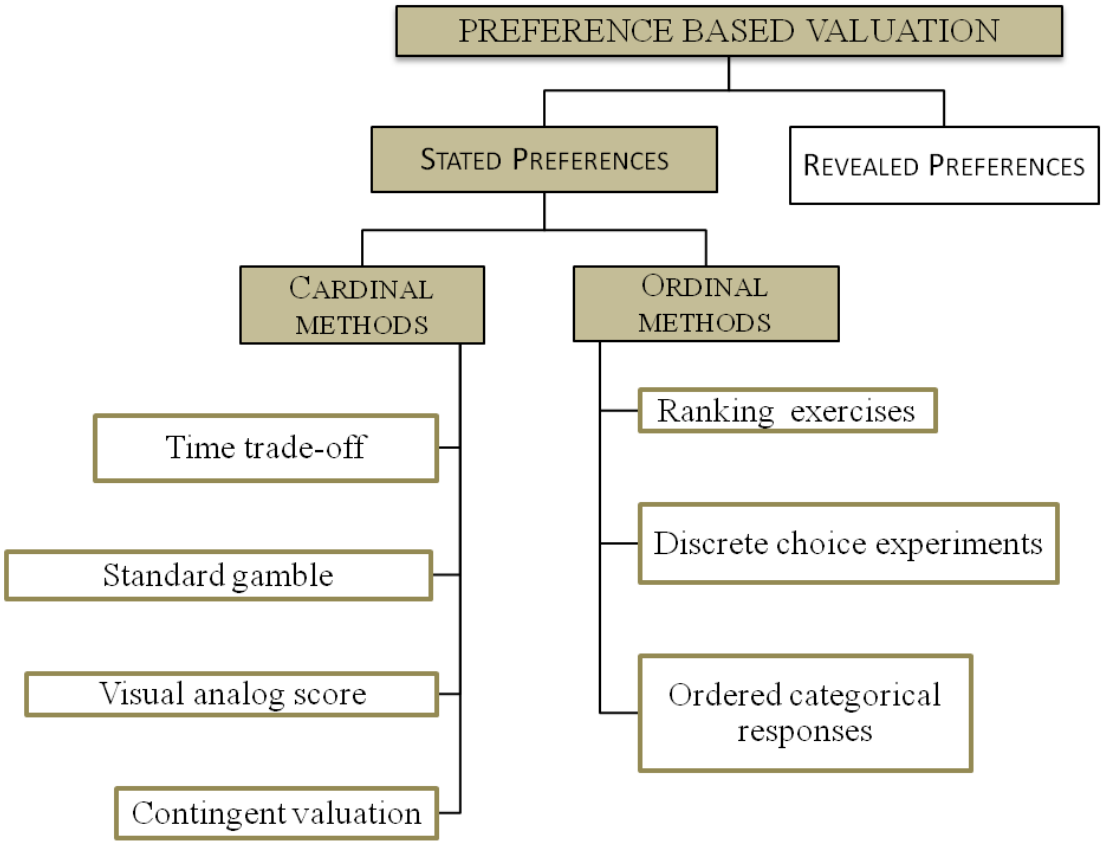


Fig.6-1: Stated Preference Methods: Adapted from Ali S and Ronaldson S (2012)

6.2.2 Cardinal methods of preference elicitation

Cardinal methods of preference elicitation are defined as those where the respondent expresses his/her utility numerically or quantitatively. Typically, these exercises can be used to elicit utilities for one health state or process at a time [200]. Examples include visual analog scores, standard gamble, time trade-off and contingent valuation methods.

Visual analog scoring (VAS)

VAS exercises involve scoring on a pre-determined scale by the respondent to indicate their preference for the given good. The scales may be numerical, categorical, vertical, horizontal (see Figure 6-2) or perhaps be a picture (e.g. visual thermometer as used in EQ-5D

quality of life measure) [203]. Although limited in its scope, VAS is a popular preference elicitation tool since it is easy and quick to complete [195, 204]. One of its major drawbacks is that it does not involve trade-offs and VAS is, therefore, not a preferred method for utility elicitation [205].

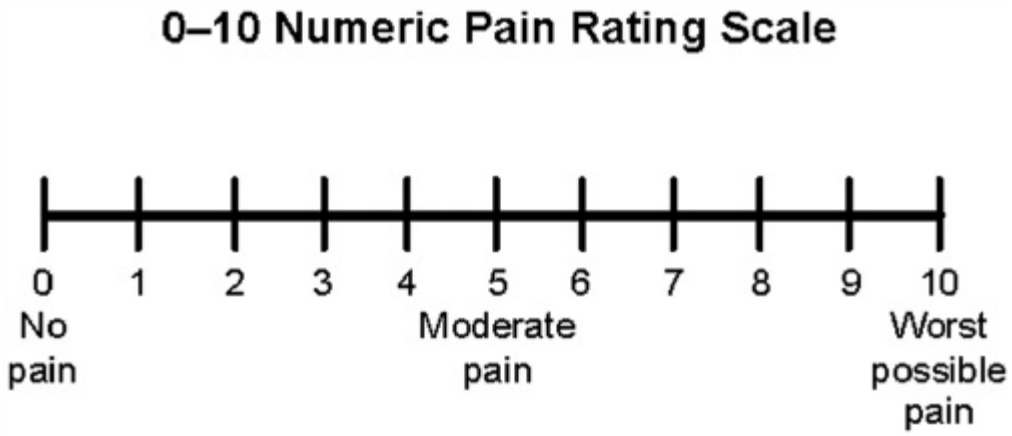


Figure 6-2: An example of a visual analogue scoring chart for pain

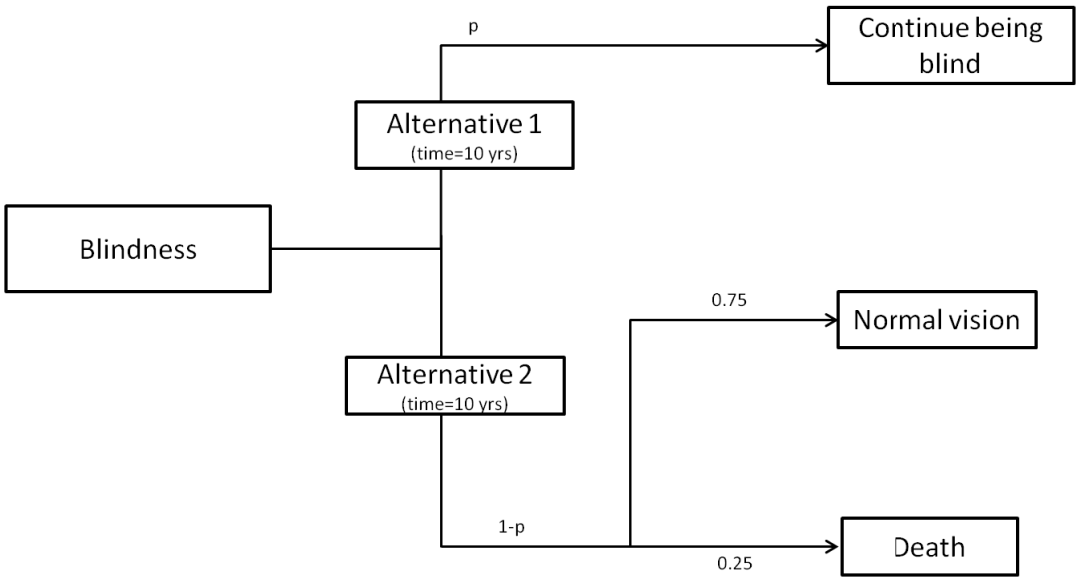
Standard gamble

A Standard gamble (SG) technique allows individuals to gamble between a period of sudden death and perfect health rather than remain in a state of poor health [206]. A typical question, for example, would be:

"Would you be willing to accept a 25% chance of sudden death and 75% chance of good vision instead of living with complete blindness for 10 years?"

The probabilities of death and full health are then altered until the person becomes indifferent to the alternatives (see Figure 6-3 below).

SG exercises are cognitively difficult, although good test-retest consistency has been reported [195]. SG assumes that all respondents are willing to trade risk of death, although in reality this may make some individuals very uncomfortable. Risk averse individuals can provide very little utility information regarding various health states in these exercises [207].

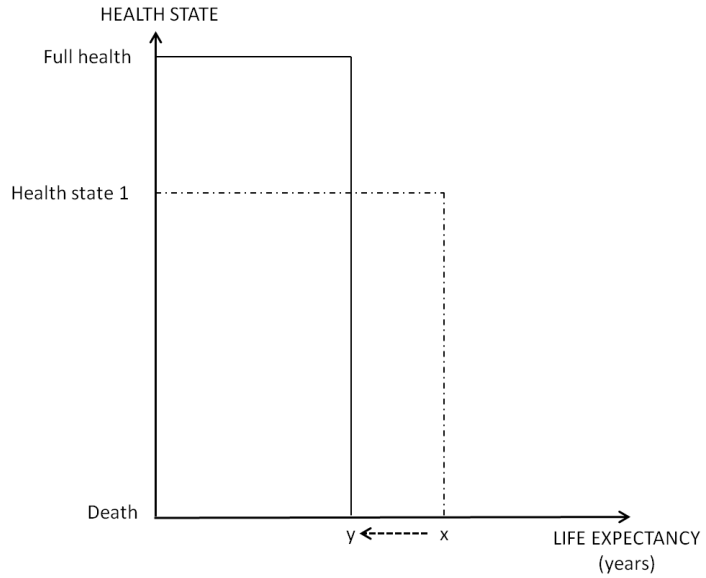


In the SG example shown, the subject is offered two alternatives. Alternative 1 would be to continue in the same health state as previously (e.g. Blindness) for a period of t years. Alternative 2 would give an option of living in full health for t years or facing the risk of sudden death. The probability (p) at which the person becomes indifferent to the two alternatives is considered the preference value for health state1.

Figure 6-3:An example of a Standard gamble exercise

Time trade- off

In a Time trade-off (TTO) exercise, the respondents are asked to quantify the amount of time they are willing to forego in order to move from a state of poor health to perfect health. (For instance, given 10 years in complete blindness, how many years of life would you be willing to forego in order to have good vision) [206]. This technique is considered easier to complete than other techniques (such as SG, see above) and is considered to have logical consistency and good test-retest reliability [208]. TTO method has been used in the valuation of UK general population tariffs for the EQ-5D [208].



In the TTO example shown above, the respondent can choose between living in health state 1 for x years or living in full health for y years (where y <x). The value of y is varied until the respondent is indifferent between the two alternatives. The preference value is then estimated as x/y.

Figure 6-4: An example of a time trade-off exercise

Contingent valuation

Contingent valuation (CV) is a direct survey approach which uses a questionnaire (or interview) to create a realistic but hypothetical market to understand the respondents willingness to pay [WTP] or willingness to accept [WTA] estimates for variations in a service (or good) [209]. The value estimates obtained in these studies are contingent on the hypothetical scenario presented to the respondents [210]. Questions can be formatted in an open-ended way e.g. "How much would you be willing to pay to see a doctor rather than a nurse at your local surgery?" However, such questions can be seen as leading and biased. For instance, the question above may be seen to assume that seeing a doctor is better than seeing a nurse. In addition, most individuals find it difficult to value non-market goods [210]. Valuing health services is especially difficult for individuals who benefit from publically funded health care systems [211].

A referendum CV, on the other hand, is designed such that respondents can either agree or disagree with a given statement. An example is shown below (Fig.6-5).

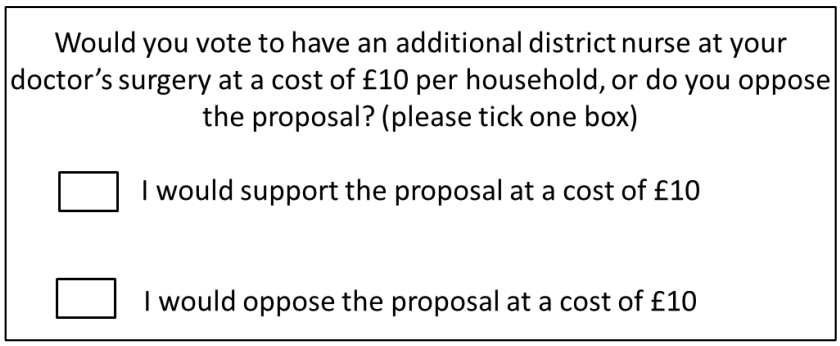


Fig.6-5: An example of a referendum CV format for health care

Although these exercises are simple to complete and can be undertaken with large numbers of individuals at a time, they have many important limitations in health valuation. Firstly, they can be used to weigh up only one attribute at a time. Secondly, WTP estimates are often found to correlate poorly to the magnitude of benefit, resulting in 'scope insensitivity' [212]. They may also vary considerably across surveys, limiting their importance as a marker of the strength of public opinion [213]. In addition, in countries such as the UK, where consumers do not commonly pay for their healthcare, WTP estimates may be blighted by 'protest voting' whereby respondents may refuse to engage meaningfully in the exercise [210, 211].

Overall, one of the main criticisms of cardinal methods of preference elicitation is the restrictive design that allows respondents to consider only one particular characteristic or process at a time. That is, these techniques do not provide reliable information regarding the relative desirability of one good compared with another [213]. Choosing between different attributes allows respondents to consider opportunity costs and therefore provides a better understanding of strengths of preference for individual characteristics. This can be especially useful in planning new service pathways where several options exist. Estimating the strength of preference can be achieved using ordinal methods, some of which are described below.

6.2.3 Ordinal methods of preference elicitation

In contrast to the cardinal methods, ordinal methods require respondents to order preferences without attempting to quantify their degree of preference for one alternative over the other [200]. Ordinal preference exercises are generally less cognitively challenging for respondents compared to techniques such as TTO and SG, which demand a very high degree of abstract reasoning [214]. However, it should be noted that responses in ordinal preference elicitation studies rely strongly on the respondent's understanding about individual conditions/characteristics included in the study and their willingness to trade-off between them [200].

Examples of ordinal methods include:

Ranking exercises

In this method, respondents may be provided with a set of alternatives and be asked to provide a complete ordering of the choices ranging from the best to the worst and the states in-between [215]. For example, respondents may be given details of different health states (such as total blindness, total deafness, major depression, rheumatoid arthritis and dementia) and then asked to rank them from most disabling to least disabling.

Whilst ranking methods are easy to carry out and to complete, they only provide utility (or desirability) information regarding one condition relative to another [216]. Detailed information regarding preferences (e.g. which characteristic of a condition would make it more or less desirable than another?) cannot be provided by this method.

Best-worst scaling (BWS)

BWS is a type of ranking exercise where the respondent is requested to identify the best and the worst attributes amongst those provided [217]. An example is shown below (Fig 6-5).

Best feature	FACTORS REGARDING THE DRUG	Worst feature
x	Route of intake: oral	
	Number of doses: 2 per day	
	Side effects : moderate	
	Out of pocket cost: £10 (per month)	
	Duration of treatment: 4 weeks	x

In the BWS example above, the respondents are asked to choose the most and least desirable attributes regarding a given service or good.

Figure 6-6: An example of best-worst scaling exercise.

BWS allows respondents to trade-off between choices at the attribute and level stage. Some researchers prefer BWS since they are cognitively less cumbersome compared to other stated preference methods and also allow respondents to weigh up all the attributes and levels against each other. However, BWS is a relatively new technique and more experience will be needed to fully understand its strengths and limitations [218].

Ordered categorical responses

Using a defined set of response categories (such as excellent, good, fair and poor for example), respondents are asked to value the combination of attributes in a given choice set. For example, a 'good' clinic may have a moderate waiting time to see a consultant whereas an 'excellent' clinic may have a short waiting time to see a consultant with dietician support within clinic [214]. Whilst this is also considered a cognitively easy task to complete, ordering of these data does not provide information regarding the strength of preference [198]. For example, the difference in strength of preference between excellent and good may be different from that between fair and poor.

Choice experiments

Choice experiments involve asking respondents to choose between different bundles of attributes rather than rating or ranking them [196].These techniques force respondents to trade-off some characteristics in favour of others. Most of the choice methods were described under the umbrella of 'conjoint analysis (CA)' in the past. However, the theoretical

underpinnings of CA are in psychology and not in economic theory [219]. CA is considered a descriptive method that attempts to fit a statistical model to a set of ranking or rating data [219]. Errors in CA are unexplainable and are considered to be ad hoc. This method does not allow for interpretation of changes to consumer behaviour in response to changes in choice [219].

The other increasingly popular choice method is the Discrete choice experiment (DCE). DCEs require respondents to choose between two or more sets of hypothetical alternatives which are described by different levels of characteristics (or attributes). Typically in a DCE, at least one attribute of the alternative is varied across respondents systematically for every choice set. The responses are then used to understand the value placed by the respondents on the levels of each attribute (see In the DCE example shown above, respondents are expected to weigh up the levels of each attribute provided and to trade-off between them to choose one particular option.

Figure 6-7) [220].

DCEs have theoretical underpinnings in the random utility theory (RUT). Unlike conjoint analysis, unexplained factors affecting choice and utility (see [Equation 6-2]) are accounted for in a DCE. Individuals are expected to trade a less favourable level of an attribute for a better version of another. In doing so, it is assumed they weigh up all the available information and then select the option that provides the highest utility value [221]. This allows the ranking of attributes against each other when setting priorities in health care [222]

The origin of DCE is also strongly rooted in psychological theory. The technique has been successfully employed in market research, environmental economics, transport economics and, increasingly in the last decade, in health services related research [222]. DCEs have been shown to be methodologically robust, with good internal validity and consistency [201].

Attribute	TV [1]	TV [2]	TV [3]
Type	Plasma	LCD	LED
Size	50 inch	36 inch	46 inch
Brand	LG	Sharp	Philips
Dealer	John Lewis	Currys	Tesco
Price	£ 450	£ 250	£ 650
Your choice	x	☐	☐

In the DCE example shown above, respondents are expected to weigh up the levels of each attribute provided and to trade-off between them to choose one particular option.

Figure 6-7: An example of a DCE.

Allergy services in the UK, as previously discussed, fall considerably short of the demands placed on them. This is especially true of paediatric allergy services, given that there are very few paediatricians trained specifically in paediatrics as well as in allergy management [15]. While it has to be acknowledged that there is a shortage of trained doctors in allergy, a broader view of service delivery may be needed if viable solutions are to be developed to tackle this crisis. Although parents interviewed in the WM were happy to see either nurses or consultants in secondary care (as discussed in the previous chapter), little is known about public preferences regarding seeing consultants (versus nurse led clinics), allergy information provision, and support services in allergy. Many aspects of a respondent's preferences can be explored in a single, well designed DCE. A simple questionnaire regarding allergy services would fail to provide information regarding the strength of preferences of the respondents for individual attributes (for example, would they prefer seeing a consultant even if it means that they have to wait longer? Do they value the need for good information more than dietician input in clinic?). A DCE is best suited in these scenarios since respondents are expected to 'trade-off' between different levels of the attributes by weighing up all the information and choosing a scenario that provides most utility [197].

A DCE was therefore planned for this study.

6.3 DISCRETE CHOICE EXPERIMENTS

DCEs in health care allow the construction of choice experiments using hypothetical market data to suit the research question [223]. They evolved out of information integration and axiomatic conjoint measurement theories in psychology and random utility theory in economics [223].

6.3.1 Theoretical underpinnings

The random utility theory states that individuals make choices in order to maximise their utility [199]. Therefore, given a choice between option i and a option j, as per the random utility model, an individual *n* would choose *i* over *j* if and only if

[*Equation 6-1]* $U_{ni} > U_{nj}$ $\forall i \neq j$

where U refers to the utility associated with the given option.

The Random Utility Model also states that an individual's utility for a given alternative can be expressed as follows:

[Equation 6-2] $U_{ni} = V_{ni} + \varepsilon_{ni}$

Where V_{ni} represents the deterministic or measurable component of the overall utility, whereas ε_{ni} represents the random or unobservable component [201]. The random component of choice could be due to observable or unobservable variables, unobserved individual characteristics (e.g. past experiences), measurement or specification errors.

Combining *[*Equation 6-1] and [*Equation 6-2*], we can infer that option i can be chosen over option j only if

[Equation 6-3] $V_{ni} + \varepsilon_{ni} > V_{nj} + \varepsilon_{nj}$

Or

[Equation 6-4] $V_{ni} - V_{nj} > \varepsilon_{nj} - \varepsilon_{ni}$

Thus the probability of choosing option i over option j (P_{ni}) can be represented as

[Equation 6-5] $P_{ni} = Pr\ (V_{ni} - V_{nj} > \varepsilon_{nj} - \varepsilon_{ni})$

Since deterministic utility is most commonly estimated using a linear utility function, the utility associated with choice i as shown in [*[Equation* 6-2*]* can be represented as follows:

[Equation 6-6] $U_{ni} = \alpha + \beta_1 x_{1n} + \beta_2 x_{2n} + ...+\beta_i x_{in} + \varepsilon_{ni}$

where α is a constant and the betas (β) provide information about the strength of preference for each attribute x within the choice set [197].

6.3.2 Choosing attributes

Various sources can be used to derive attributes for DCEs. These include expert review [224], literature search [225], informal discussions with selected stakeholders [226], discussions with service providers [227], existing policy/ professional recommendations [228], existing health outcome measures [229] and qualitative studies [230].

Interviews and focus group discussions not only allow for identification of a wide range of relevant attributes but also help define levels that apply to the particular population. Hence, the use of qualitative studies in planning discrete choice experiments has been favoured by a few opinion leaders in the field [198, 230, 231].However, given that the aim of qualitative studies (to obtain in-depth information) can be at odds with that of DCEs (to ascertain preferences using very concise or targeted attributes) [230], there may be some difficulty in directly translating qualitative data into a form that suits choice experiments. On the whole, it is important to be explicit about the source of the attributes and the reasons why they were chosen [231].

For the purposes of the current DCE, attributes were derived mostly from the qualitative study discussed in the previous chapter. The choice of attributes is further explained in the methods section of this Chapter (See section 6.5.1).

6.3.3 DCE design

A full factorial design in a DCE is one that considers every possible alternative within the choice experiment. This is only practical for small studies with very few attributes and levels

[232]. For most DCE studies, a fractional factorial design- which incorporates a selection of choice situations- is preferred. There are different types of fractional factorial designs; all of these are aimed at producing a practical number of datasets incorporating complex model specifications, where necessary [233]. Examples include orthogonal designs, D-efficient designs and D-optimal designs. All these designs provide attribute level balance (i.e., each level appears with equal frequency within an attribute) [232, 233], but vary in some significant aspects.

Orthogonal designs, for instance, ensure that each pair of levels appears with equal frequency across all attributes, providing an additional balance within the survey [233]. When orthogonal designs are unavailable or are deemed too inflexible for the given data, D-efficient or D-optimal designs are employed [234]. These use a D-efficiency score or the D-score, which is an estimate of the optimality of the proposed against a comparator design [233]. The higher the D-score, the better the model specification. D-score depends upon the coding scheme and model specification including attribute levels and interactions as well as Bayesian priors for the model coefficients specified in the design construction [233]. The model specifications strongly affect the design and the response efficiency of the model design and should therefore be carefully chosen when models using D-scores are specified [233].

Orthogonal designs are generally favoured since they are easy to construct and allow for independent estimation of the influence of each attribute on the choices of the respondents [232]. In addition, orthogonality minimises the variance of parameter estimates and ensures that the model does not suffer from multi-collinearity [232]. An additional advantage is that 'blocks' can be used when the design requires many choice sets to be given to a single respondent. For example, when the orthogonal design contains 32 choices, these can be presented to 2 respondents in blocks of 16 each or to 4 respondents with 8 choice sets per block. However, each block is not orthogonal in itself and responses should be analysed in combination with the other blocks.

Other drawbacks of orthogonality are that it can result in implausible choice situations within the survey (e.g, severe illness may be combined with good mobility or vice-versa) or produce obviously dominant choices which yield little preference information [233]. In addition, orthogonal designs completely disregard relationships between attributes. They do not support subset analysis since it is not possible to maintain orthogonality in subsets [196, 232]. Despite this, they are thought to be the most efficient and are the most commonly employed designs for DCE.

In the current study, an orthogonal design without blocking was used in the pilot studies as well as in the final survey.

6.3.4 DCE participants

The results of choice experiments can vary based on the respondents chosen. For example, an exercise involving the public, doctors and NHS managers revealed considerable disagreement with regards to the ranking of services in the order of priority [215]. Whilst the public prioritised heart transplant operations and intensive care treatment for premature babies, doctors and managers gave more importance to antismoking education for children[215].Many DCEs in the past have surveyed patients [228, 235, 236] although more recently there has been a trend towards surveying taxpayers or public [224, 237]. Surveys of patients generally reveal strong preferences towards non-health outcomes or processes, whereas the public (or taxpayers) tend to prefer health focused attributes [238].

There are other issues to consider while recruiting participants into DCEs- these exercises can be cognitively challenging and therefore, individuals with impaired cognition such as those with acute psychotic schizophrenia or dementia cannot be included in these studies [233]. DCEs require participants to have (or be able to acquire) a good understanding of the attributes and levels being described in order to be able to trade-off as expected. Hence the design of these questionnaires should be given ample thought, with sufficient information given to respondents regarding the attributes while ensuring that they do not lose interest. Multiple iterations and pilot studies are needed before design can be finalised [223]. Since

the explicit objective of DCEs is to be able to measure preferences beyond health [239], it is important that the study population be carefully chosen after considering the study objectives and the possible limitations (e.g. generalisability) [238]. For example, a study assessing preferences for breast cancer follow-up would recruit individuals who have been diagnosed with breast cancer [240] whereas preferences for GP access could be elicited from general population [237].

Since the current study aimed to understand parent preferences for paediatric allergy specialist services in the WM region, parents of children aged between 0 to 16 years residing in the region were recruited from the general population.

6.3.5 Sample size

There are no definite guidelines on how sample sizes can be estimated for choice experiments. Orme et al. proposed a 'rule of thumb' technique [241] to calculate the minimum sample size (N) for a DCE which can be expressed as

[Equation 6-7] $$N = 500 \frac{max(L_k)}{J \, x \, T}$$

Where J is the number of alternatives per choice set, T is the number of choice tasks, L_k is the maximum number of levels per attribute k.

However, published DCE literature suggests that responses in healthcare surveys are more variable and heterogeneous [242] compared with DCEs in other areas (such as transport or environment). Therefore larger sample sizes are needed. In addition, where blocking is used in surveys (see section 6.3.3), sample sizes need to increase accordingly.

The statistical efficiency of a DCE can be improved by increasing the total number of responses either by increasing the number of choice sets per respondent or by increasing the sample size within the study [233]. Since the former can result in reduced response efficiency (due to respondent inattention or fatigue), increasing sample size is a preferred option for improving the predictive power of a DCE [233].

Figure 6-8 shows the effect of simulated sample sizes from three separate healthcare DCEs on the estimate precision [233]. Researchers plotted the mean precision estimates against different sample sizes for each of the datasets [243]. It is clear that although the studies had different mean precision estimates, there was a rapid increase in precision up to sample size of 300 and further increases accrued very small increments in precision.

A sample size between 300 and 500 was planned for this study in order to allow for statistical analysis within a minimum acceptable level of statistical precision (standard error <0.05).

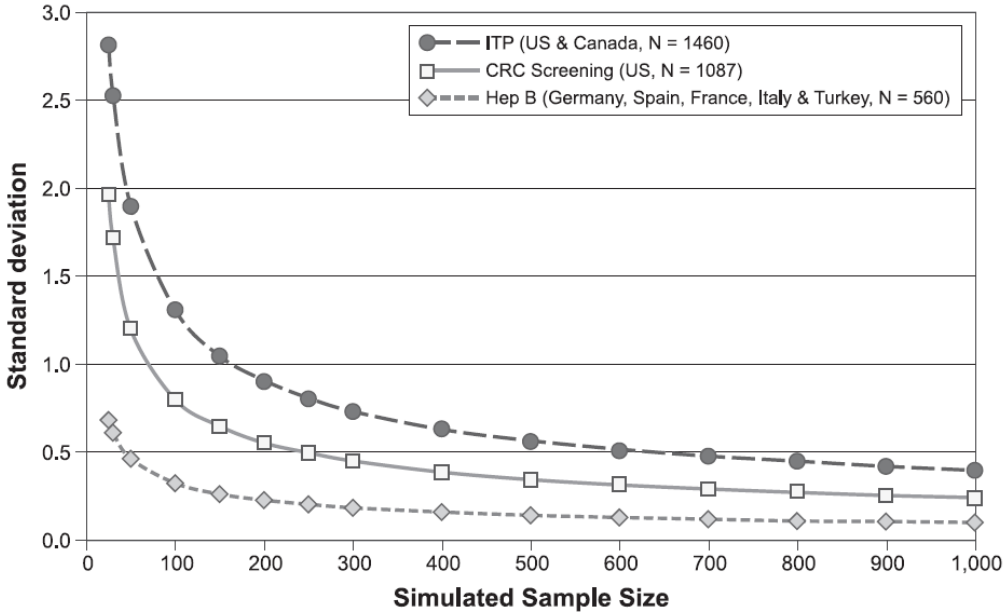


Figure 6-8: Effect of sample size on precision estimates of DCEs. This figure is taken from Johnson et al[233].

6.4 OBJECTIVES OF THE STUDY

1. The main objective of this study was to ascertain the values placed by parents from the WM region on selected attributes relating to paediatric allergy specialist services.
2. Other objectives included understanding how these preferences vary for:
    - Parents who have children with allergies

- Parents who have an income of £43,000 or more per year (i.e., over the HMRC threshold for high income earners for England in 2016)
- Parents who have experienced secondary care services for their children (in any disease area)

6.5 METHODS

6.5.1 Attribute development

The qualitative study that contributed to the development of attributes for the DCE is discussed in detail in Chapter 5. The themes directly relating to allergy service delivery are discussed in section 5.4.3. Since the overall aim of this work to provide recommendations for improving specialist services, four of the six attributes were chosen to be included in the DCE. The rationale for this choice as well as that of the levels of the attributes is shown in Table 6-1. Attribute development evolved as the pilot analyses were carried out and responses and suggestions were accrued. In addition to attributes from the qualitative study, an attribute related to out of pocket costs was included in the study in order to calculate the willingness to pay estimates from the responses. Although four different levels of costs were used in the pilot surveys, only three of these (£25,£50 and £100) were included in the final survey as discussed in Table 6-2 since respondents strongly rejected the £200 option during pilot surveys.

6.5.2 Sample size

As per the Orme equation ([Equation 6-7]), given that this study had 2 alternatives per choice set, 18 choice tasks per individual and a maximum of 3 levels for attributes (see Table 6-1 and Section 6.5.3), the minimum sample size required was estimated to be 42 [500 x (3/ 2x18) = 42].

However, in order to ensure statistical efficiency a greater sample size was deemed necessary. A minimum sample size of 300 was aimed for as discussed in 6.3.5 .

Table 6-1: Attributes chosen for the DCE from the qualitative study

Theme	Reason for choosing (or omitting) attribute	Levels	Rationale for levels and notes
Being taken seriously	No.; Taking patients seriously (or not) is an attitude trait of doctors and therefore is not amenable to intervention.	Not applicable	Not applicable; This theme was not deemed suitable for the DCE.
Clinician seen in hospital	Yes. Parents had mixed reactions about seeing nurses in clinic rather than consultants.	Pilots 1-3 Nurse specialist Consultant Final survey Nurse specialist- allergy trained Consultant (not trained in allergy) Consultant (allergy trained)	Nurse specialists are cheaper to train than consultants. They are generally well received although a few patients prefer to see a doctor. However, a significant proportion of paediatric allergy services in the UK (and WM) are provided by paediatric consultants who may or may not be formally trained in allergy. After discussion with colleagues and appraising literature, this level was added after pilot 2 to provide a more realistic option for service provision.
Receiving timely healthcare	Yes. Access to specialist care was described as an issue during the interviews.	Pilots 1-3 8 weeks 12 weeks 18 weeks	The UK Department of Health stipulates that patients should wait no more than 18 weeks to see an NHS specialist after initial referral for a non-emergency appointment. The demand on allergy specialist

		Final survey 8 weeks 12 weeks 18 weeks	services are high and waiting times below 8 weeks are currently unrealistic. These options remained the same for the pilot and final surveys.
Support with allergy management	Yes. Parents often required additional services to help with the management of issues related to allergy (e.g. changes to diet if food allergy; dermatology input for eczema; psychologist input for children with anaphylaxis)	Pilots 1-3 No additional support Dietician only Dietician+eczema support Final survey No additional support Additional support available	Some specialist clinics offer dietician services within the same appointment. Others have good access to dermatology services. These were included in the survey given their importance to the management of allergies. However, after discussion with colleagues and reviewing responses from pilot surveys, it was felt that the access to additional services was a more important factor than the make-up of these services. This is especially true since the need for additional services can vary depending on the clinical needs of the child.
Issues with information	Yes. Some parents complained of a paucity of information regarding allergy.	Pilots 1-3 No information Verbal information only Verbal+ Written information Final survey Improved NHS.net website Verbal information Detailed written information	Parents mentioned the need for more information provision in clinics. A few parents felt that they received very little information and hence the 'no information' option was included in the pilot studies. However, based on feedback, it was decided to drop this option since it was felt to be unrealistic (since some information is imparted at any clinical appointment). Some parents in the qualitative study

			mentioned the lack of information on trusted websites such as NHS.net. Others were happy to search the internet themselves for information although some were wary of this approach. Although this was initially not included, it was later added as per feedback from pilot studies.

Table 6-2: Cost attributes used in the study

Attribute	Levels	Rationale
Out of pocket costs	Pilot 1 None	Cost attributes were not included in the initial pilot. However, after consulting literature and discussing with colleagues experienced in the use of DCEs in health care (such as Prof Ryan from Aberdeen) it was felt that cost attributes could be important to the study. Using monetary attributes within DCE helps understand the willingness to pay for the various attributes and levels. The levels were chosen arbitrarily, with the highest cost reflecting about half the estimated cost of a private specialist appointment. A higher rate (£200) was used in the pilot analysis, but respondents found the cost too high and were not able to trade this level off other attributes and levels, (i.e.) the choice set with £200 was not being chosen irrespective of the options given with other attributes. This was therefore dropped for the final survey.
	Pilots 2-3 £25,£50, £100, £200	
	Final survey £25,£50,£100	

6.5.3 Choice of design

Within the final DCE there were 5 attributes; 4 with 3 levels each and 1 attribute with 2 levels (see Table 6-3). Therefore a full factorial design (i.e., a design that incorporates all possible different choice situations) would have to include [(3x3x3x3x2) x (3x3x3x3x2)= 3^8x2^2] 26,244 combinations of choice sets. Clearly, this would neither be feasible nor practicable. An orthogonal design (see section 6.3.3) was specified using Ngene® software (see Appendix 6.A for details) which determined that a questionnaire containing minimum of 18 choice sets would be needed for the final survey.

Table 6-3: Attributes and levels used in the DCE (main study)

Attribute	Levels
Clinician seen	Nurse specialist- allergy trained Consultant- no allergy training Consultant- allergy trained
Allergy information provided	Improved NHS.net website Verbal information Detailed written information
Additional support in clinic	Additional support available No additional support
Waiting time for clinic	8 weeks 12 weeks 18 weeks
Out of pocket costs	£25 £50 £100

6.5.4 Developing the questionnaire

Multiple pilot surveys using volunteers from the University of Birmingham were carried out in order to optimise the survey questionnaire. The questionnaire had 3 sections as shown in Table 6-4.

The initial surveys (Pilots 1, 2 and 3) were carried out using surveymonkey® software.

Ngene® software (Version 1.1.2; ChoiceMetrics Ltd) was used to specify the design of the choice experiment . This survey employed an orthogonal design.

Table 6-4: Layout of the DCE survey

Section 1	Welcome and brief introduction to the survey Explanation about paediatric allergy services and a brief note regarding each attribute within the study
Section 2	A brief explanation on how to answer the choice part of the questionnaire Choice sets
Section 3	Demographic questionnaire Thank you Eligibility for amazon vouchers (pilot 4 and main population survey only)

6.5.5 Ethics approval

Pilot surveys 1,2 and 3 were aimed at questionnaire development and included only colleagues. Hence these did not warrant ethics approval. Ethics approval was obtained from the University of Birmingham for the interim population survey (pilot 4) and for the final survey (reference: ERN_16-1181). The approval letter is included in the appendix (6.B).

6.5.6 Pilot surveys

Pilot survey 1

The first pilot survey was aimed at ascertaining whether or not the respondents could understand the background information provided. An initial email was sent to colleagues within the Institute of Applied Health Research [IAHR] in the University of Birmingham requesting the participation of those who had children aged less than 16 years. Those who volunteered were sent a shortened version of section 2 (7 choice sets), but with the full versions of Section 1 and 3. Cost attribute was not included (see Table 6-3). Volunteers were requested to provide feedback either via email or directly to the principal investigator (LD).

Pilot survey 2

A further survey using colleagues was carried out using the modified sections 1 and 3 and the complete section 2 [36 choice sets]. Colleagues who responded to this survey may or may not have had children under the age of 16.

Pilot survey 3

A 'Think aloud' study was carried out using 1 volunteer from the University of Birmingham. The respondent was given brief instructions regarding the study and was advised to complete the survey whilst the investigator stayed in the room. She was encouraged to verbalise her thoughts while completing the questionnaire. The think-aloud exercise was recorded although the hand notes made by the researcher during the exercise proved adequate for analysis.

6.5.7 Final survey

Population survey

The population survey of parents was carried out with the help of a market research company called M.E.L. Research [244]. The company was commissioned to contact parents of children under the age of 16 years in the WM region on behalf of the investigators. Ethical approval was obtained from the University of Birmingham for the study (see section 6.5.5). Since NHS patients were not recruited, NHS ethics was not required (see Appendix 6.B)

Contact data for individuals are obtained by the research company through data suppliers. Individuals who 'opt-in' to take part in surveys are registered onto a database by the contractors. The contact information for these individuals is updated by the data suppliers' every 12 months, so that only those individuals who are willing to remain in the database can be contacted. Unlike a few other market survey companies, each individual participating in this survey was not paid for their participation. However, respondents who completed the survey were eligible for inclusion in a prize draw for a gift voucher. Participation was voluntary and those who wished to be taken off the panel (to avoid further emails) could do so by contacting either the researcher or the company directly.

An interim analysis was carried out after 75 responses were received in order to ensure that the respondents did not have difficulties with understanding the survey and completing it. The respondents were also requested to answer two specific questions regarding the questionnaire - "How was the format of the questionnaire?" (choices included too easy,

neither easy nor complicated, too complicated) and "How long was the questionnaire?" (choices included too short, just right, too long).

If the interim results showed that the questionnaire was well understood and was fairly easy to complete, it would be sent out to a larger proportion of parents across the WM.

6.5.8 Data storage and transformation

Data were received by the researchers from the third party (i.e. M.E.L. Research) who provided anonymised and coded responses in .xls format to the researcher (LD) for the analysis. These data were transformed into .dta files for statistical analysis. Password protected university computers were used for data storage.

6.6 DATA ANALYSIS

6.6.1 Analysis of the pilot studies

The objective of the initial pilot (instrument development) surveys was to ensure that:

- The formatting of the questionnaire was sound with all the attributes explained in a clear and concise manner
- All the important attributes were included within the survey
- The choice sets were easy to understand and respondents could trade-off attributes as expected within the study
- The DCE was theoretically valid - i.e., higher levels of willingness to pay and longer waiting times were not preferred by the respondents.
- The objective of the interim analysis (pilot 4) was to confirm that:
    - The survey was being understood by the unselected group of parents and that the trade-offs followed *a priori* expectations.
    - The respondents did not find the survey either too difficult or too long.

6.6.2 Quantitative analysis

In a DCE, each individual is expected to choose from a series of choices and thus multiple observations are available for analysis from each respondent. Hence, multinomial random effect models such as probit, logit, clogit are preferred in observable utility estimation in DCE [245]. Of these, conditional logit (or clogit)has been shown to be consistent with the random utility theory. It has been specifically developed to relate choices with the utility of attributes within the choice models and is generally preferred in DCE analysis [246].

Following from [*Equation 6-5*], the probability of choosing option i over option j using logit model can be shown as follows:

[*Equation 6-8*] $$P_{ni} = \frac{\exp V_i}{\sum_{j=1}^{n} \exp(V_j)}$$

Conditional logistic regression in this study was carried out using Stata15® (Statacorp, USA). The dependant variable was choice (i.e., whether or not the option was chosen) and the independent variables were the attributes. The regression coefficients obtained from the analysis reflect the utility value estimates for each attribute. The size of the coefficient represents the extent of preference and the sign on the coefficient reflects whether the given attribute level increases or decreases utility compared with the baseline level [236]. The difference between coefficients demonstrates the utility of one attribute level compared to another [221].

6.6.3 Coding in DCE analysis

Effects coding and dummy coding are two commonly used methods for categorical coding within a DCE. In both of these approaches, one level within each attribute is used as the reference point for estimating the utility values for the other levels [223]. In dummy coding, there may be an issue with identification of the omitted and reference variables leading to errors in intercept estimation, which is dealt with in effects coding. This is explained in some detail in Appendix section 6.C.

The issue of errors in intercept estimation does not apply when conditional logit estimation (which suppresses intercepts for groups) is used. Effects coding does not provide additional data in this situation and was therefore not used in this analysis.

6.6.4 Marginal rates of substitution

The marginal rate of substitution of a given attribute is an estimation of the strength of preference for that attribute in relation to the overall utility associated with the choice. Marginal utility χ of an individual attribute (k) can be shown as follows:

[*Equation 6-9*] $$\Delta V/\Delta X_k = \chi_k$$

This is represented by the beta estimates (β) within the clogit equation.

The difference between marginal utility estimates for the different attributes provides an estimate of preference of one attribute over the other [247].

Including a cost attribute in the DCE allows for the estimation of willingness to pay (WTP) values for the different attribute levels. This is a monetary value that provides a common metric against which all the attribute levels can be compared and is intuitively better understood as strength of preference for the given attribute.

The WTP estimates can be calculated as follows:

[Equation 6-10] $$WTP_k = {}^{\chi_k}/_{\beta Cost}$$

where χ is the marginal utility for attribute k and βCost is the utility estimate for the cost attribute.

6.6.5 Subgroup analysis

In this analysis, the respondents were divided into subgroups based on certain characteristics (income level, whether or not they had a child with allergy, whether or not they have accessed paediatric secondary care services) and the data re-analysed to estimate utility values for each of these groups [248].

6.7 RESULTS

6.7.1 Pilot survey1

A total of 20 colleagues across the University of Birmingham were sent a link for the survey via email. A reminder was sent at the end of week 1 and week 2 respectively to the non-responders. 17 responses were received, an overall response rate of 85%. Colleagues commented on the format of the survey overall, the explanations given about the various attributes, the levels used and the overall design of the survey. Only 7 choice sets per respondent were included in this pilot and no cost related attributes were presented. Some of the suggestions/ comments received are shown in the appendix (6.D).

6.7.2 Pilot survey 2

Of the 84 people emailed with a link for this survey, 27 responded (32%). This survey had 36 choice sets. The questionnaire was also sent to selected colleagues who have some experience with choice experiments in order to obtain more specific and in-depth comments (see Appendix 6.E). Almost all the respondents found the survey too long and tedious. They also commented on some specific attribute levels (e.g. "No information" at a clinical appointment was felt to be unrealistic as every clinical consultation would be expected to provide some information).

An *a priori* assumption was made for the study that increasing waiting time and costs would be undesirable to the respondents. This was checked by carrying out a clogit analysis of the pilot data. The graphs shown in Figure 6-9 demonstrate that the results were in keeping with this hypothesis.

6.7.3 Pilot survey 3 (Think aloud study)

The participant commented on how long the questionnaire was. She felt that the explanations given regarding allergies were complex and not amenable to quick reading. Some of the pictures provided during the explanations were distracting. She found the questions repetitive and got bored part way through. The £200 option for out of pocket costs

was dominating her choices. She felt that weblinks to allergy related websites for further information (for those interested) at the end of the survey may be useful.

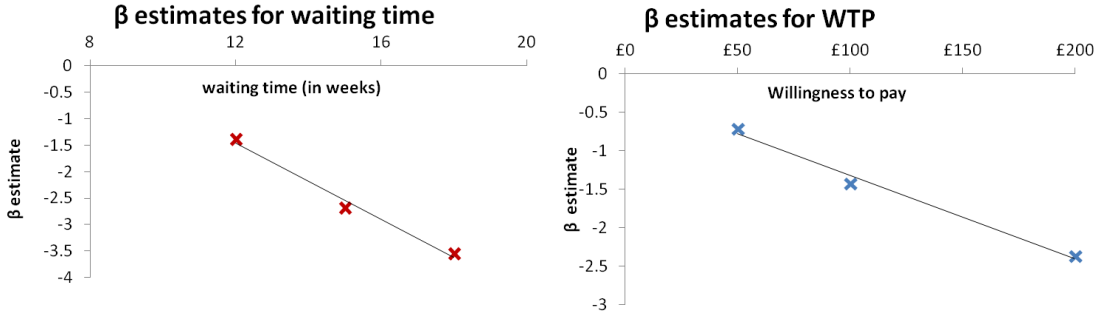


Figure 6-9: Trends in the β estimates for waiting time and willingness to pay in pilot survey 2.

6.7.4 Population survey (Interim analysis)

Using data from pilots 1,2 and 3, a DCE questionnaire (Appendix 6.G) was finalised. Interim analysis was carried out on the first 75 completed responses of the population survey to ensure that the questionnaire was generally easy to complete (Table 6-5).

Table 6-5: Impressions regarding questionnaire: Interim analysis of population survey

Questionnaire specifics	N(%)
How did you find the questionnaire?	
Very easy	59 (78.7)
Neither easy nor difficult	15 (20)
Very complicated	1 (1.3)
How long did you find the questionnaire?	
Too short	1 (1.3)
Neither short nor long	57 (76.0)
Too long	17 (22.7)

A clogit regression analysis was carried out to estimate the utility values associated with the levels within the waiting time and cost attributes to ensure that the apriori assumptions were met (Figure 6-10).

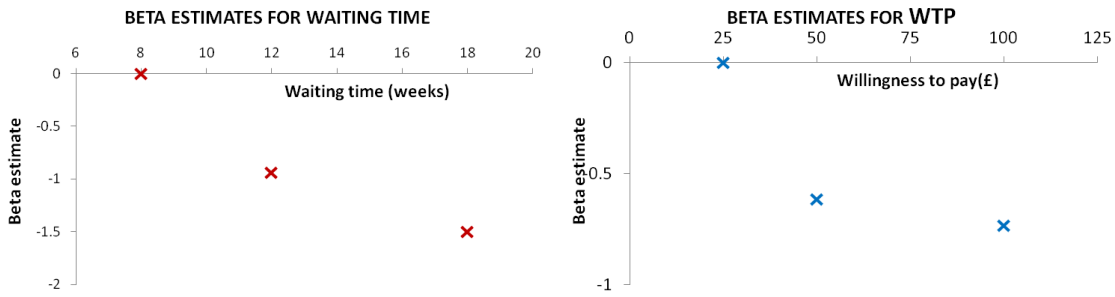


Figure 6-10: Trends in β estimates for waiting time and cost: interim analysis of population survey

The results from the interim analysis were deemed satisfactory and no further changes to the questionnaire format or content were made. The questionnaire was sent out to a larger population sample with a view to obtaining a total of at least 300 responses (including those used in the interim analysis).

6.7.5 Population survey (Final analysis)

Data from pilot surveys 1, 2 and 3 were not included in the final analysis.

A five attribute, two alternative, forced choice DCE was sent to 10,000 members of the general population deemed suitable for the study (parents with children under age 16 years residing within the WM) by the survey company. Most individuals (9,499; about 95%) did not open the email at all. Of the 501 who clicked on the survey, 176 (35.1%) did not answer any questions, 34 (6.8%) were not eligible (did not have children), 11 (2.2%) started the survey but did not complete it, 280 (55.9%) completed the survey. Thus, 280 valid responses were received, an overall response rate of 2.8%. The response rate amongst those who acknowledged the survey was 55.9%.

The demographic characteristics of the respondents are summarised in Table 6-6. Most of the respondents were female, white and employed, aged between 35 and 55 years. Each respondent had an average of 1.5 children (SD=0.21). About half of the respondents had children with allergy and/ or eczema. About 40% had children with asthma.

Table 6-6: Summary of demographic characteristics of individuals providing completed responses for the DCE.

Characteristic	N (%)
Total	280 (100)
Female	244 (84.1)
Age group	
18 to 24 yrs	7 (2.5)
25 to 34 yrs	51 (18.2)
35 to 44 yrs	124 (44.3)
45 to 54 yrs	93 (33.2)
≥ 55yrs	5 (1.8)
Children age[$]	
0 to 1 yrs	28 (10)
2 to 5 yrs	96 (34.3)
6 to 10 yrs	137 (48.9)
11-16 yrs	165 (58.9)
History of allergy or related conditions	
Child with eczema	139 (49.6)
Child with asthma	110 (39.3)
Child with allergy	145 (51.8)
Consulted GP for allergy or eczema	119 (42.5)
Consulted hospital consultant for allergy/eczema	
Never	189 (67.5)
In the last 1year	44 (15.7)
In the last 2 to 5 yrs	47 (16.8)
Annual household income	
0 to 18,500	61 (21.8)
18,500 to 23,000	43 (15.4)
23,000 to 30,000	32 (11.4)
30,000 to 43,000	41 (14.6)
more than 43,000	63 (22.5)
Prefer not to answer	40 (14.3)
Education*	
No education	10 (3.6)
Entry level (including A level)	124 (44.3)
Higher education	110 (39.3)

Employment status*	
Employed	193 (68.9)
Not employed (incl student, retired)	17 (6.1)
Looking after home/family	50 (17.9)
Ethnicity*	
White	176 (62.9)
Black	17 (6.1)
Asian	68 (24.3)

[$]*Respondents may have more than one child under age 16 yrs *May not add up to 100% since only major categories included*

The results of the conditional logit analysis for the DCE are shown in Table 6-7. The *a priori* assumptions discussed previously (decreasing utility values with increasing waiting time and out of pocket costs) were satisfied in the DCE.

Utility values for each of the levels are measured against a baseline level as shown:

Table 6-7: DCE results: Utility values for levels of various attributes in the DCE

Attribute	Utility scores	Std error	95% CI
Person			
Nurse specialist (allergy trained)	(Reference)		
Consultant-no allergy training	-1.289***	0.053	-1.39 to -1.18
Consultant - allergy trained	0.578***	0.053	0.47 to 0.68
Information			
Improved NHS choices website	(Reference)		
Verbal information	-0.631***	0.056	-0.74 to -0.52
Detailed written information	-0.497***	0.054	-0.60 to -0.39
Support			
No additional support	(Reference)		
Additional support available	0.277***	0.044	0.19 to 0.36
Waiting time			
8 weeks	(Reference)		
12 weeks	-0.781***	0.056	-0.89 to -0.67
18 weeks	-1.20***	0.057	-1.31 to -1.09
Out of pocket costs			
£25	(Reference)		
£50	-0.6***	0.054	-0.71 to -0.50
£100	-0.722***	0.055	-0.83 to -0.61

*** *P<0.0001*

All the attributes and levels included in the DCE were good predictors of choice ($p<0.0001$ for all). The highest preference weight (or utility score) was associated with seeing a consultant trained in allergy. Longer waiting times (up to 18 weeks) were seen as particularly undesirable, associated with second worst utility values in the DCE (Table 6-7).

A specialist nurse consultation had higher utility scores and was hence more preferred than consultation with a consultant not trained in allergy, although a nurse was less preferred than a consultant trained in allergy. Detailed written information in clinics was valued higher than being provided with verbal information only. However, improving online information through websites like NHS choices was the most preferred option for accessing allergy information in

the DCE. Respondents preferred to have supportive care (availability of dietician or dermatology nurse) within the same clinic appointment. Shorter waiting times and lower out of pocket costs were preferred. However, respondents did not differentiate too much between out of pocket costs of £50 and £100.

Consulting an allergy specialist nurse rather than a consultant not trained in allergy provided 3 times more utility and consulting a trained allergy consultant yielded 4.5 times more utility than reducing the waiting period from 18 to 12 weeks. The preference weights for seeing a nurse (as opposed to a consultant not trained in allergy) were the same as those for reducing the weighting time from 18 to 8 weeks. This suggests that respondents were willing to wait longer to see practitioners who were specifically trained in allergy.

Having a better NHS choices website rather than written information was about twice more desirable compared with having additional support in clinic.

6.7.6 Marginal rates of substitution

Willingness to pay or accept estimates (WTP or WTA respectively) were calculated for each of the levels of the attributes. These are shown in Table 6-8. In essence, all those levels which have a WTP estimate are preferable compared with the comparator level whereas WTA estimates suggest that the comparator level is more acceptable than the proposed one.

For instance, seeing a consultant who was not trained in allergy in secondary care was less preferable to seeing a nurse specialist or an allergy trained consultant. Seeing an consultant trained in allergy compared with one not trained in allergy had a WTP estimate of £218.9 (-151.1 to -67.8), which was higher than the WTP estimate for reducing waiting time from 18 weeks to 8 weeks (£141.2). In other words, respondents seemed to value seeing an allergy consultant even if they had to wait quite long to do so. Similarly, respondents preferred to wait up to 18 weeks to see an allergy specialist nurse rather than see a consultant who was not allergy trained.

An improved NHS website information regarding allergy and related conditions was more preferred than having additional support within an allergy clinic.

Table 6-8: Willingness to pay or receive estimates for each level of the attributes

Attribute	WTP *(£)	Lower CI	Upper CI
Person			
Nurse specialist (allergy)	Comparator		
Consultant-no allergy training	-151.1	-163.3	-138.9
Consultant - allergy trained	67.8	55.5	80.1
Information			
Improved NHS website	Comparator	-	-
Verbal information	-72.7	-85.4	-59.9
Detailed written information	-54.3	-66.6	-41.9
Support			
No additional support	Comparator	-	-
Additional support available	30.0	19.8	40.1
Waiting time			
8 weeks	Comparator	-	-
12 weeks	-90.2	-102.9	-77.4
18 weeks	-141.2	-141.2	-154.3

**Positive monetary values suggest that the alternative is preferred to the comparator level (WTP); Negative values indicate that the comparator level is preferred (WTA)*

6.7.7 Subgroup analysis

Logistic regression analysis performed after dividing the respondents into subgroups as discussed in section 6.4 did not show significant variations from the baseline analysis. The highly preferred options (Allergy trained consultant, improved NHS choices website for information, need for additional clinic support and preference for lower waiting times and costs) were the same for all the subgroups analysed. The results are shown in appendix Table 6.F.

6.8 DISCUSSION

6.8.1 Principal findings

This study found that the parents in WM strongly preferred to see consultants trained in allergy in specialist centres. They also strongly preferred to have improved, reliable online information regarding allergies, additional services for allergy (such as dietician and dermatology support) and shorter waiting times to see specialists. Least preferred options were consultants who were not specifically trained in allergy and long waiting times.

A DCE was used to ascertain these preferences. Using DCE to understand preferences of the general public regarding health service delivery and service pathways has been explored previously [226]. This DCE is the first, to our knowledge, to focus on preferences for paediatric allergy specialist services.

One of the themes that emerged in the qualitative study – being taken seriously- was not included in the DCE. This is because it was felt that this characteristic would not be amenable to change via intervention (all medical students are taught to take their patients seriously). Also, previous studies have shown that an option such as this could dominate choice in a DCE [249]. This is unsurprising because all other options could be rendered meaningless if a doctor does not take their patient seriously. In terms of informing policy, it was felt that the conclusions of the qualitative study provided evidence compelling enough to make a case for improved training. Inclusion of this theme in the DCE, therefore, was not felt necessary.

There are some very important findings in this study that can directly inform allergy service pathways. Firstly, parents strongly preferred to see a clinician trained in allergy rather than a consultant who had no formal allergy training. Allergy services in the UK are currently delivered mostly by consultant allergists and immunologists, but a significant proportion of service delivery is borne by other specialists (e.g. dermatologists, respiratory physicians, ENT specialists) with no formal training in the field [6]. This is especially true for paediatric allergy where the trained specialist numbers are even lower [19, 114]. This heterogeneous spread of specialists can result in unequal access to care and treatment across the country.

Training more nurses in allergy can improve pathways of care whilst keeping the costs down [8]. Indeed, the qualitative study discussed in Chapter 5 suggested that parents in WM region were happy for their child to be reviewed by specialist nurses in secondary care. The DCE confirms this while showing that parents are willing to wait longer to see a trained nurse or consultant.

The second important finding was that improving NHS choices or reliable information websites was favoured strongly over the other two options in the questionnaire (provision of verbal or detailed written information). Better health education and improved communication with clinicians leads to more patient satisfaction as well as improved health and non-health outcomes [250, 251]. Whilst it is possible that there was a selection bias given that this was a web based survey of parents with young children, it cannot be denied that the internet is becoming an increasingly popular medium for the delivery of information *per se* [252]. Individuals use information technology in different ways, based perhaps on age, the underlying health condition and familiarity with web based tools [253]. For instance, about 60% of young adults surveyed in a study in France used the internet as a source of health information instead of or before seeing a doctor [254]. Respondents in an Australian study of web users with chronic medical conditions used the internet to manage their health as well as to clarify the information given by their physician [255]. Literature suggests that unmet information needs in allergy can lead to increased consultations with doctors [256] and greater anxiety regarding management of the condition [257]. Thus, there are clear incentives to improving the availability of evidence based information regarding allergies to the public. The internet is a relatively easy route for the delivery of such information, although many individuals are concerned about the reliability of most web based information outlets [253]. However, more effort should be made to improve the allergy data available on the NHS choices or similar reliable websites that are well respected by the UK public.

Parents also preferred to have additional services (such as dietetic support, dermatology advice for eczema) in the allergy clinic. Allergy amongst UK (and WM) children, as shown

through analysis of the THIN database (see Figure 3-17) is becoming increasingly complex. More children now present with a combination of allergic conditions such as food allergy, eczema and asthma. In order to provide these children with the care they require, it is important to have multi-disciplinary teams providing input into their management [6, 7]. A report from the Royal College of Physicians suggested that only trained specialists could provide such a holistic service and recommended that more multi-specialist centres for allergy be commissioned [6]. However, the investment needed to achieve this has not been forthcoming. Very few clinics in the WM are able to provide parents with dietetic input and referrals to dermatology services where necessary (see section 1.2). This study suggests that parents value these inputs.

The waiting times to see allergy specialists throughout the WM region are very long. Most clinics have waiting periods of at least 18 weeks, some are even longer (personal communication with Dr Goddard, Consultant Immunologist, UHNM). Parents are, not surprisingly, averse to long waiting times. However, it is interesting to note that they are willing to wait up to 18 weeks to see a consultant trained in allergy rather than an untrained one.

6.8.2 Strengths and limitations of the study

This study provides data regarding parental preferences that are directly relevant to planning allergy services in the WM. It shares principles of shared decision making and is the first study that aimed to understand population preferences for allergy specialist services. The attributes for the study were derived from a qualitative study, which ensured that they were relevant and important to the local service pathways. Indeed, *clogit* analysis showed that all the attributes and levels included in the DCE were important predictors of choice ($p<0.0001$ for all).

There are some potential limitations of the study, however. The recruitment rates were very low (overall rate: 2.8%). It should be noted that in most surveys of this nature, response rates are not made explicit [258, 259]. However, the proportion of individuals who completed

the survey once the email was opened was 56%, which is perhaps above average for an online survey [260]. This may, in part, be due to the offer of a post-survey incentive (a chance to win a £25 Amazon voucher if the survey were to be completed). It could be argued that the size of the sample is less important than its representativeness [261]. About 50% of those who completed the survey had a child with either allergy, asthma or eczema and about 20% had consulted a hospital specialist for this condition. This suggests that there may have been some self-selection bias with the responses, although these proportions are perhaps in keeping with the current prevalence figures for these conditions (see Chapter 3).

Some DCEs rely on paid panel survey members to complete the questionnaires, which may result in higher response rates [262]. Panels offer incentives per completed response which may lead to problems with data integrity (e.g. false answers, answering too fast, choosing the same option repeatedly). The use of general public rather than professional panel responders was therefore preferred in this study [263].

In a DCE, it is assumed that the respondents understand all the options provided to them in order to trade-off rationally between them [202]. However, some respondents may be fixated on a single attribute and may be unwilling to trade [264]. Although a great deal of effort was put into the design of the DCE and the explanations provided to the respondents beforehand (see Appendix 6.G), it is possible that these were either not read completely or understood sufficiently. Even though the a priori assumptions of the DCE were met and most of the respondents felt that the survey was easy to understand and to complete, it cannot be guaranteed that all respondents were able to consider opportunity costs before making their choices.

6.8.3 Strengths and limitations in relation to other studies

There are no published DCEs looking at preferences for allergy pathways. There are, however, a few published choice experiments focused on patient or public preferences for health pathways. Examples include a study assessing preferences of pregnant women for home versus hospital delivery [265], understanding public preferences for out-of-hours

primary care [266], ascertaining preferences of vascular surgery patients for locally based care packages [267]. These studies, similar to the one discussed in this chapter, can inform commissioners about the preferences of stake holders regarding health services. Another strength of the study is the way out of pocket costs were explained and laid out (see Appendix 6.G). Unlike a few other studies where cost attributes resulted in 'protest voting' [236], the parents understood the concept of willingness to pay in the current study and traded off the costs estimates as was expected.

6.8.4 Future research

For a better understanding of local priorities, a preference elicitation exercise involving GPs and perhaps commissioners may be useful in service planning.

6.9 CONCLUSIONS

Parents in the WM prefer to consult secondary care clinicians who have received formal allergy training for their children. Consultants who are not formally trained in allergy were not favoured. Parents were willing to wait longer to see trained clinicians. Access to allergy related educational resources on reliable websites was the preferred option over verbal and written information; Additional support for children with allergy (such as dietetics and dermatology) was also favoured.

Discrete choice experiments have the potential to inform patient/ public preferences for health pathways. When systematically planned and executed, they can provide useful data regarding preferences of various stakeholders within health services. They can play a key role in improving shared decision making and should be considered when new services or investments are being planned.

The findings from the systematic review, database analyses, qualitative review and the DCE are summarised in the next chapter. Current pathways for WM paediatric allergy services are outlined and changes proposed to improve these services.

7 DISCUSSION

This thesis presented an in-depth insight into the current state of paediatric allergy services in the West Midlands. Analysis of databases was carried out, end users were interviewed and opinions of parents were sought in order to propose a service redesign. This chapter brings together the findings from the thesis. Implications of these findings for allergy pathways and clinical practice are discussed. The strength and weaknesses of the study are highlighted and areas needing further research are outlined.

7.1 SUMMARY OF FINDINGS

This thesis evaluated paediatric allergy pathways in the WM. The principal findings from the research are summarised in relation to the objectives identified in Chapter 1 (see section 1.3).

7.1.1 Objective 1: To understand the modes of delivery of allergy services worldwide; to explore the challenges, success stories and the future directions for service delivery

This objective was addressed by a systematic review described in Chapter 2. The review found that allergy services globally are not meeting the escalating demands due to increasing prevalence of allergies and related conditions [19]. The lack of specialists in allergy across the world and particularly the EU has been highlighted repeatedly in the literature.

A majority of studies included in the systematic review were published in the UK [19]. It is somewhat surprising that despite the intense interest in the topic and the recognition that services need improvement, that very little progress has actually been achieved during this period. Indeed, there has been not been a notable increase either in the number of qualified specialists or in the number of trainee doctors in the specialty (see section 2.3.2). There has been no national drive to include structured allergy training in the curriculum. Given that an estimated 30% of all current UK adults and 40% of children will experience some allergic disorder during their lifetime [47], the training provided to doctors currently is woefully inadequate.

The review also revealed that, the lack of training in allergy amongst General Practitioners is a particularly pertinent issue [19]. GPs are the gatekeepers to NHS specialist services and the review highlighted that their lack of confidence and, in some cases competence, in the management of allergies is a source of great distress to patients (section 2.3.1). This also creates inefficiencies in the care pathways for allergy since specialist resources, scarce as they are, are not particularly well utilised. Therefore, from Chapter 2, it was surmised that increasing the number of specialists alone without improving other aspects (such as GP

training in allergy, empowering patients for self management) cannot improve services (section 2.3.2).

A hub and spoke model of service delivery was championed in most of the initial reports. However, the review in Chapter 2 identified no evidence to suggest that this is a suitable model for NHS allergy services. Allergy is mostly managed in primary care with a small proportion of individuals referred for specialist management. In order to improve the overall service delivery, it is imperative that concerted efforts be made to improve knowledge and resources available to primary care practitioners for the diagnosis and management of their patients with allergy. Education of patients to improve self-management should also be prioritised. In Finland, this approach produced considerable improvement in patient outcomes for asthma over a 10 year period despite an overall increase in asthma prevalence in the country [59].

7.1.2 Objective 2: To understand the current demands placed on NHS services due to paediatric allergy in a) the UK or England and b) the West Midlands (WM)

Chapters 3 and 4 scrutinised and discussed the analysis of two large NHS databases (THIN and HES) to estimate the extent to which paediatric allergy and related conditions are reviewed in primary and secondary care. The data showed that while incidence rates for most GP diagnosed allergies and related conditions remain stable, allergy prevalence (based on GP data) amongst children is increasing in the UK as well as in the WM (see Figure 3-4 and Figure 3-8). The analysis showed that the overall burden and trends in prevalence of allergic disease across the UK are similar to those seen in children in the WM, except that allergic rhino conjunctivitis (ARC) is more commonly diagnosed in the WM (Figure 3-16). Nevertheless, the proportion of children who receive allergen specific immunotherapy (which is a proven clinically effective and cost effective treatment for ARC [137]), is much lower in the WM than that of the English average (Figure 4-6).

The increasing allergy prevalence highlighted in chapter 3 directly impacts the demand for allergy services. Whereas asthma prevalence has remained more or less stable, the prevalence

of ARC and food allergy have more than doubled between 2000 and 2015 (see Table 3-3). Nut allergy rates have more than trebled, with a 275% increase during this period. Nearly one in 3 children in the UK is being diagnosed with eczema by their GP by the age of five and nearly one in four children has received a diagnosis of ARC by the age of 15 years (Table 3-5). One in six children has been diagnosed with urticaria at least once by age 15. In addition, the proportion of children with complex allergies has increased considerably, both in the UK and in the WM (Table 3-4).

Analysis of the Hospital Episodes Statistics (HES) database revealed that the number of children being admitted to NHS hospitals with allergy related diagnoses has increased during the period 2008-2014 (Figure 4-2) (Figure 4-5). As shown in previous publications using the HES database, it is clear that children aged 5 or under are more likely to present with anaphylaxis, about 60% of these have food related reactions [122].

Chapter 4 showed that elective hospital admissions for allergy, specifically for allergen immunotherapy or desensitisation treatments, have increased steadily between 2008-2014 and this perhaps reflects the general willingness amongst secondary care practitioners to provide these disease modifying treatments for ARC, given that they are safe and effective. However, the number of children overall receiving these treatments is still substantially low suggesting that the paediatric allergy services in England and particularly the WM are poor (see section 4.6.3).

7.1.3 Objectives 3 and 4: To understand experiences and preferences of parents regarding paediatric allergy services in the WM

In Chapters 5 and 6, a qualitative study of parents who had accessed secondary care allergy services for their children and a discrete choice experiment (DCE) of parents in the WM region were discussed respectively.

The qualitative study revealed that parents face many barriers accessing primary and secondary care services. Although the narrative depended strongly on the underlying allergy, appointments with GPs were difficult to obtain for some parents and most experienced long

waiting lists before they could see the specialist. GPs were sometimes ill informed about allergy diagnosis and management, leading to considerable stress and anxiety for parents (see 5.4.3). Lack of access to reliable information regarding allergies prior to seeing a specialist meant that parents were left with many weeks of being unable to manage their child's condition effectively. Websites such as NHS choices were deemed inadequate by parents and the credibility of other sources of information on the internet was suspected. The qualitative work also revealed that parents were often quite anxious about the management of their child and were particularly worried about delegating child care to other individuals who may or may not take their child's allergies seriously . Where the children had food allergies, parents found labelling of foods in supermarkets confusing leading to a considerable impact on household shopping and budget (section 5.4.4).

A discrete choice experiment (Chapter 6) carried out with parents in the WM revealed that parents were willing to wait longer to see trained allergy practitioners in secondary care compared with consultants not formally trained in allergy. They also strongly preferred web based educational tools to written and verbal information and also preferred multi-disciplinary clinics (see 6.7.5).

7.2 STRENGTHS AND LIMITATIONS OF THE STUDY

The main strength of this study is its systematic approach to service pathway evaluation and evidence synthesis including a systematic literature review of allergy service pathways worldwide; a structured analysis of primary and secondary databases to understand current demand on paediatric allergy services and to predict future trends of the pressures on the service; and a qualitative synthesis and DCE to understand the experiences of individuals currently accessing these services in the WM and ascertaining the preferences of end users for specialist services for paediatric allergy.

The study brings together various resources (e.g. large healthcare databases) and techniques (systematic review, qualitative techniques, discrete choice experiment) to comprehensively understand the strengths and weaknesses of current pathways for service

delivery in the WM. The techniques used in this study are generalisable for not just allergy service pathways across the UK but also for health pathway assessments in other areas.

The systematic review appraised all published English literature regarding allergy pathways across the world. However, there were no eligible publications for this review from the Americas, Australia, large parts of Asia and Africa. Data from low and middle income countries were conspicuously missing. There were only three prospective studies and none had a control group. Studies not reported in the English language were excluded. It was nevertheless, the first review to scrutinise allergy pathways, highlight their advantages and drawbacks and identify models that are most likely to be successful for service delivery.

Analysis of the primary care database (The Health Improvement Network or THIN database) presented in Chapter 3 provided longitudinal data on over 1.5 million children over 15 years (2000-2015). GP diagnosed allergy incidence and prevalence trends for children in the UK as well as the WM were estimated. The Hospital Episodes Statistics database (HES) analysis presented in Chapter 4 provided 87,000 finished admission episodes data over a period of 7 years (2008-2014). Estimates for trends in emergency and elective admissions into English (and WM) NHS hospitals were derived from this dataset.

Both THIN and HES record diagnoses made by qualified medical practitioners. However, as with any other large database of routinely collected information, there can be issues with accuracy of the diagnosis, coding and also problems with missing data. Although the datasets reflect NHS related activity across UK and England respectively, there are no data assessing the accuracy and generalisability of regional estimates of disease burden using these datasets (particularly THIN). In addition, most allergy in the UK is self-managed by patients in the community and analysis of these databases may not provide an accurate estimation of either the population burden of disease or the disease pathways.

The qualitative study (Chapter 5) was the first to evaluate experiences of end users relating to primary and secondary care allergy services. The study interviewed 18 parents, mostly mothers, to understand the barriers to accessing paediatric allergy services in the WM region.

Experiences of parents with primary care for their child's allergy varied considerably across the region. Only two specialist centres, both with trained allergy specialists, were included in the study. This may partially explain the high levels of satisfaction expressed by parents in relation to secondary care. However, the study did highlight the considerable problems that parents in the WM face not only accessing allergy services but also with everyday care of their children.

Data from the qualitative study were used to plan the discrete choice experiment (DCE) described in Chapter 6. This DCE is the first to elicit public preferences for regional paediatric allergy services. Although the response rates for this study were low, the respondents appeared to trade-off appropriately between the various attributes and levels and all the levels used were found to be significant predictors of choice ($p<0.0001$; see section 6.7.5). The use of results from qualitative study to populate the DCE ensured that the attributes most relevant to the regional services could be chosen and therefore the results obtained can be directly applied to service planning.

This thesis presents the first systematic evaluation of a regional health service pathway. However, some crucial gaps in evidence remain. This thesis does not provide data on attitudes of local commissioners regarding allergy services in the region. Nor does it explore the opinions of service providers (GPs and specialist physicians/ nurses) regarding allergy pathways or services. Pharmacists, who have an important role in enabling patient self-management, were not included in this evaluation.

Comparisons between this study and the published literature could not be made since no other studies which have assessed service pathways in this manner could be identified.

7.3 INTERPRETING THE RESULTS OF THE RESEARCH

This thesis provides an important insight into the current challenges facing paediatric allergy services in the WM. The focus on the regional services was deliberate since specialist availability varies widely across the UK and little was previously known about the regional

variations in allergic disease and service availability. However, the techniques used in the study are robust and are generalisable to other regions as well as other aspects of healthcare in the UK and elsewhere.

7.3.1 Implications for clinical practice

The work presented in this thesis has shown that the demands on paediatric allergy services across the country are increasing and that there is an upward trend in disease prevalence amongst children. In addition, the proportion of children with complex allergies is also increasing (Chapter 3). Patients with allergy are finding it difficult to access both primary and secondary care allergy services (Chapter 5). Access to reliable information regarding allergies was also difficult for the parents interviewed in this study (Chapter 5). Parents in the WM preferred access to web based education tools and were willing to wait longer to see a specialist who has formally been trained in allergy (Chapter 6).

However, as discussed in chapter 2, there is a serious shortage in specialist availability in allergy and this shortage is likely to continue for the foreseeable future. Most specialist clinics have very long waiting times currently and this is bound to worsen if no specific interventions are put in place.

Given these constraints, a pragmatic approach towards improving services is needed. Since the main aim of allergy pathways is to enable self-management, clear and effective educational material should be made easily accessible to allergy sufferers in the community. GPs should be provided with readily accessible and relevant educational material which can improve their diagnostic and management skills for allergies and related conditions (e.g. online continuing medical education modules in allergy aimed at primary care physicians).

More efforts should be made to tackle inefficiencies in the current allergy care pathways. A large proportion of patients who are currently referred to specialists for allergies can be managed effectively in primary care [13] through patient education and improving GP knowledge of these conditions. Providing a specialist nurse (or consultant led) allergy

advisory service aimed at reducing referrals from GPs may be useful, although a similar scheme was not particularly successful in Ireland [40].

All specialists with an interest in providing allergy services should be required to have some formal training in the subject. This is vital for an overall improvement in service quality not only across the WM but in the UK as a whole. Formal assessments similar to the European examination in Allergology and Clinical Immunology [58] should be made mandatory for consultants expecting to look after allergy patients. In addition, collaborations could be set up between various medical Royal Colleges to develop a competency based training scheme for specialist trainees (or consultants) interested in providing allergy services.

7.3.2 Implications for service pathways

The data from this research (primarily presented in chapters 3 and 4) suggest that there will be steadily increasing demand on paediatric allergy services across the country in the next few years. This research has shown that access to secondary care is poor in England, particularly in the WM region.

In an era of unprecedented financial cuts within the NHS, the idea of a service overhaul is bound to be viewed with some scepticism and, perhaps, weariness. However, findings from this research suggest that considerable dividends can be obtained in the longer term by making some relatively inexpensive changes to service pathways. These include improving undergraduate medical student, pharmacist and nursing training in the management of common allergies, as well as improving training of GP trainees in allergy. Such initiatives are necessary since a third of all UK adults (and a higher proportion of children) are expected to be diagnosed with at least one allergy or related condition during their lifetime. The prevalence of allergy amongst UK adults is considerably higher than that of diabetes (9%) [268] and heart disease (under 5%) [269]. Focussing some attention toward improving the undergraduate and GP curriculum with regards to allergy training deserves much consideration.

The other important issue highlighted in this thesis (Chapter 5) is the lack of educational resources for patients. Allergy related information, especially those available on trusted websites such as NHS choices should be improved. More information regarding web based resources should be made accessible to GPs so that these can then be cascaded to patients as appropriate. The rapid ascendancy of the world wide web and its popularity with the younger generations -including young parents belonging to the so-called millennial generation, has not been harnessed adequately by the NHS. More should be done to use social media and well established and trusted web spaces to improve education and empower these individuals to manage their health conditions, including allergies, better.

Other measures which are needed to improve services in the medium and longer term will require some initial investment. These include expanding specialist training in allergy to generalists (e.g. paediatricians) and interested specialists from other fields. Formal assessment for certification and regular CME activities should be mandated for all specialists practising allergy. Clinical allergists and immunologists could provide much needed oversight for clinical pathways for the region by managing complex patients, being part of multi-disciplinary teams, providing niche services (such as drug allergy tests or management of severe urticaria). This would ensure that all practitioners are competent and that patients get the appropriately robust advice that they are entitled to when they are reviewed by a secondary care physician. In addition, targeted initiatives with financial incentives such as commissioning for quality and innovation (CQUIN) can be employed to improve allergy services. It is interesting to note that there have been no allergy related CQUINs to date which perhaps reflects the low priority that allergy services have hitherto received. Such initiatives would need a coordinated effort between the Royal colleges (of physicians as well as child health) with a leadership role from a national allergy society such as the BSACI.

More specialist nurses should be trained to ease the burden on allergy services. Appropriately trained nurses were more preferable to consultants not formally trained in allergy to parents in the WM. Many of the UK reports discussed in the systematic review

(Chapter 2) have highlighted the underutilisation of nurses in the delivery of allergy services. Specialist nurses can provide a very competent service at a relatively lower cost to the NHS [270]. Most nurse led services will need consultant support, however, and this can be provided in person or remotely via regular case/ service discussions.

Importantly, implementation of these initiatives should be done systematically, with a good deal of thought given to the ways in which the effects of such changes can be measured. Where possible, trials with suitable control groups should be planned to ensure that true effects of interventions can be measured. Clustered randomised trials or multicentre controlled trials can be planned for service evaluation where appropriate. Other models such as difference in difference studies [271] may also be suitable when regional pathways are modified.

7.4 AREAS FOR FUTURE RESEARCH

Although there is a lot of important work being done to understand the underlying causes of allergy, research into allergy clinical pathways and service delivery has been largely ignored in the past. More efforts should be made to identify and tackle inefficiencies in service pathways. Qualitative work involving primary and secondary care physicians aimed at identifying inefficiencies in the current care pathways will help identify areas that can be improved. Since there are many competing interests involved in the evolution and planning of service pathways, qualitative studies can be combined with Discrete Choice Experiments to understand the strength of preferences of different stakeholders for various aspects of allergy management.

Decision analytical modelling can be used to better understand the inputs and the outcomes of various service pathways. Exploration of uncertainties within the model using probabilistic sensitivity analysis, cost effectiveness acceptability curves can provide much information regarding the relative efficiency of different pathways. Econometric analyses such as value of information analysis can help identify areas within the model that can

provide best value for research. Bayesian priors can also be used to understand the impact of service alterations on outcomes.

Patient involvement should be actively sought in allergy research. A majority of allergies can be self-managed in the community and the need for patient input into the development of tools to enable this cannot be over-stated. A priority setting partnership such as those championed by the James Lind Alliance [272] involving patients and/ or carers, primary and secondary care practitioners can be very useful and informative in directing future research into allergies and service pathways.

Conventional quality of life instruments such as EQ-5D and SF-6D aimed at measuring Quality Adjusted Life Years (QALYs) are not sensitive enough to measure the beneficial effects of such initiatives in allergy management. Symptoms associated with conditions such as hay fever, even if severe, are seasonal and therefore may not be adequately captured using QALY measures. This has a direct impact on the resource allocation decisions made for allergy management and therefore needs to be addressed in the future. Efforts should be made to develop newer and more relevant questionnaires such as the Juniper quality of life questionnaire for allergic rhinitis [273] and the 7 day Urticaria Activity Score (UAS7) [274]. Development of patient reported outcome measures (PROMs) has been gaining some momentum in allergy [275] and requires further investment. These instruments will help establish agreed goals for disease management. They will also help ensure a more consistent assessment of services which, in turn, can help reduce heterogeneity in service pathways.

7.5 CONCLUSIONS

Paediatric allergy services in the UK are disparate and are currently inadequate to meet the demands placed on them. With the rising prevalence of allergies, including complex allergies and life-threatening manifestations such as anaphylaxis, more needs to be done to improve services in the WM as well as across the UK. There was much focus on hub and spoke model of service delivery in the past, but this is unlikely to be a good model for the UK. Improving patient self management through developing effective shared learning pathways,

improving knowledge of GPs with regards to allergy diagnosis and management, ensuring all specialists offering secondary care services are adequately trained in the disease area will be important for the much needed upliftment of services. Patient involvement in planning allergy service is necessary. Ensuring that physicians and patients work in partnership with each other is vital for the success of allergy pathways anywhere.

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Appendix

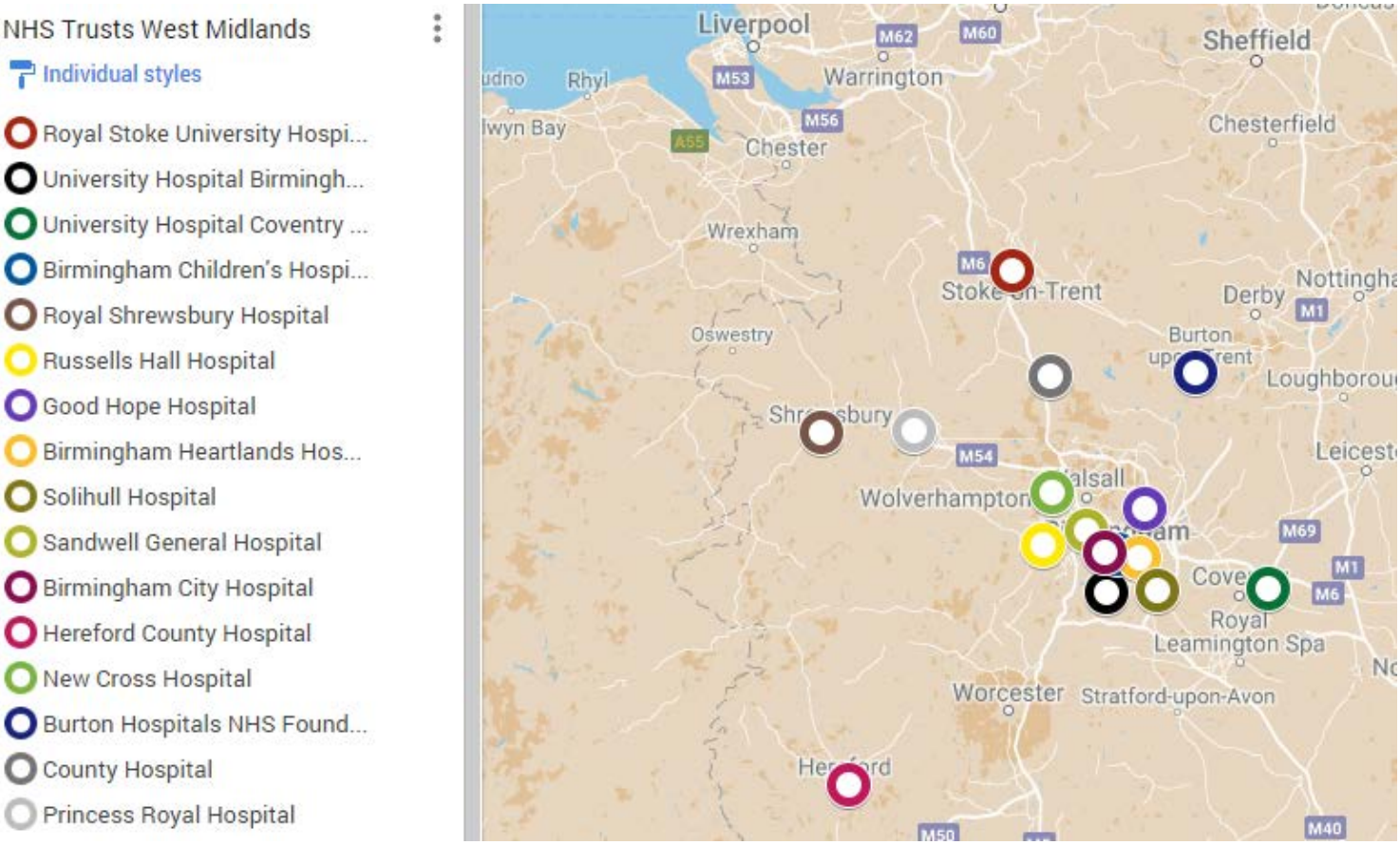


Fig1.A: A map showing all the NHS Trusts offering paediatric allergy services within the West Midlands region

2.A: PRISMA CHECKLIST FOR THE SYSTEMATIC REVIEW

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2,3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	NA
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	NA
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5,6
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5,6
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	S2
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6

Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	6
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	NA
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	NA
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	NA
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	NA

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

2.B: SEARCH STRATEGY EMPLOYED FOR MEDLINE DATABASES (OVID AND EMBASE)

1.	allerg*.hw,sh.
2.	eczema.hw,sh.
3.	1 or 2
4.	(care adj pathway*).mp.
5.	3 and 4
6.	(servic* adj pathway*).mp.
7.	(allerg* adj service*).mp.
8.	5 or 6 or 7
9.	conference abstract.pt.
10.	8 not 9
11.	limit 10 to human
12.	limit 11 to english
13.	Remove duplicates from 12

CINAHL SEARCH STRATEGY

S1	TI allergy
S2	TI service
S3	TI care
S4	S2 or S3
S5	(MH "Health Care Delivery") OR (MH "Health Resource Allocation") OR (MH "Health Care Reform") OR (MH "Health Services Purchasing") OR (MH "Managed Care Programs") OR (MH "National Health Programs") OR (MH "Primary Health Care") OR (MH "Telehealth") OR (MH "Health Care Delivery, Integrated") OR (MH"Health Services Administration")
S6	(MH "Health Services Administration") OR (MH "Patient Care") OR (MH "Protocols") OR (MH "Nursing Protocols") OR (MH "Patient Care Plans")
S7	"design"
S8	(MH "Community networks") OR (MH "Hospitals, Community") OR (MH "Community Assessment) OR (MH "Health Information Networks") OR (MH "Community Role") OR (MH "Community Health Centers")
S9	S5 OR S6 ORS7 OR S8
S10	S4 AND S9
S11	S1 AND S10

2.C: DATABASES USED IN THE SYSTEMATIC REVIEW

DATABASE	PUBLISHER	TIME FRAME	WHAT IS COVERED?
EMBASE	Elsevier	1947- present	Biomedical and Pharmacological publications covering more than 90 countries; Especially strong in coverage of drug and pharmaceutical research.
Ovid Medline	US National Library of Medicine	1946- present	Updated daily; Access to over 5,600 biomedical and life sciences journals in nearly 40 languages (60 languages for older journals). English abstracts are included in more than 80% of the records.
Cumulative Index to Nursing and Allied health literature [CINAHL]	EBSCO host	1961- present	Literature covers a wide range of topics including nursing, biomedicine, health sciences librarianship, alternative/complementary medicine, consumer health and 17 allied health disciplines. Indexing for over 3,100 journals
Database for Abstracts and Dissemination [DARE]	NIHR centre for Reviews and Dissemination [CRD]	1994- 2015	Includes CRD assessed reviews and Cochrane reviews; Access to over 35,000 quality assessed systematic reviews of health and social care interventions ; Summaries of all Cochrane systematic reviews and protocols are available up to March 2015
NHS Economic Evaluation Database [NHS EED]	NIHR centre for Reviews and Dissemination [CRD]	1994-2015	CRD assessed economic evaluations; Over 17,000 economic evaluations of health and social care interventions are available
Health Technology Assessment database [INAHTA]	NIHR centre for Reviews and Dissemination [CRD]	1989- present	The NIHR HTA database provides free access to bibliographic information about ongoing and published health technology assessments commissioned from around the world. The database provides a comprehensive listing of over 15,000 in progress and published health technology assessments.

2.D: DATA EXTRACTION TABLES: Summary of characteristics of the included publications (Arranged in chronological order)

Author, (Year) (Ref)	Region	Type of study	Study Aim	Level 1⁰	Level 2⁰	Salient Findings	Key Recommendations	Comments
Isinkaye et al (2016)(50)	UK	Retrospective cohort study	To ascertain what proportion of referrals to secondary care could be managed a by GP with special interest in allergy.	✓		– At least two-fifths of all referrals to specialists (42%) were felt to be appropriate for a GPwSI setting. – There was some disagreement between reviewers re: suitability of a further 30% of the referrals – Intra observer variation was also seen (i.e. reviewer changed their initial opinion on referral after seeing the letter from specialist) –	– GPwSI in allergy could effectively identify and manage a large proportion of referrals made to paediatric allergy specialists – This service should be introduced alongside other initiatives to improve UK allergy services	– The GP referral letters and the clinic letters from specialists were reviewed by 3 paediatric allergists – Generalisability of results may be an issue, although GPwSI shown to be useful by Levy et al as well. – The authors used an agreed set of criteria for the competencies expected of a GPwSI (not provided with the paper)
Krishna et al (2016)(44)	UK	Report/ non-systematic literature review	To discuss the potential use of telemedicine in pathways for diagnosis and management of adult allergies	✓	✓	–Adult allergy services can potentially benefit from telemedicine. Various pathways are suggested –Algorithms for possible management of allergic rhinitis, urticaria and anaphylaxis via telemedicine are discussed	–Authors advise that prospective studies evaluating these techniques should be planned	– Telemedicine used successfully in some areas of medicine, but systematic prospective studies in allergy are lacking – There are potential issues with clinical governance and confidentiality Lack of adequately trained specialists can affect implementation of these measures
Bousquet et al (2015)(40)	Europe	Introduction of prospective study using Information and communications technology (ICT) methods	Plan for study with ICT methods in allergy services	✓	✓	–Many gaps in allergy diagnosis and management exist which could be addressed using advances in ICT –The use of Visual Analog scoring, e-allergy and MASK aerobiology appscan help in diagnosis , management and monitoring of allergic rhinitis	– The systems will be based on ARIA and International consensus of rhinitis guidelines – The use of ICT can facilitate communication between clinicians, patients, pharmacists and other stakeholders	– This project aims to use ICT systems to tackle heterogeneity in AR management across Europe – The clinical trial is being planned; but the uptake of ICT in other studies has been poor
Conlan et al (2015)(39)	Ireland	Retrospective cohort study	review of 1)new allergy referrals to adult specialist clinic 2) a pilot email communication service with non-specialists	✓	✓	–A majority of patients referred to secondary care had chronic spontaneous urticaria or angioedema –Food / drug allergy or intolerance accounted for about a quarter of all referrals –The email service did not show demonstrable impact on referral numbers –It was rated as useful by those clinicians who responded to the survey	– Studies examining referral patterns can be helpful in planning services locally by targeting education of non-specialists. –New models of care delivery should be tried to help ease demand on specialist allergy centres	– Study designed to help service planning locally- design may be generalisable whereas findings are not – The uptake of email service was perhaps lower than expected. Also the response rate to the survey was poor (35%)- which makes the usefulness of the service difficult to gauge.

Author, (Year) (Ref)	Region	Type of study	Study Aim	Level 1⁰	Level 2⁰	Salient Findings	Key Recommendations	Comments
House of Lords Science and Technology Committee, 6th report of session 2006/7 (2007)(18)	UK	Report from a publicly funded organisation	To explore the impact of allergy in the United Kingdom upon patients, society and the economy as a whole.	✓	✓	– Allergy exerts a considerable social and economic burden upon the nation. – There is a severe shortage of allergy specialists in the UK and the services lag far behind those of many countries in Western Europe. – There are problems with data collection rendering statistics imprecise and affecting service redevelopment plans – There has been a chronic lack of training of PCPs and medical trainees in allergy, leading to problems with diagnosis and management at the primary care level. – Further research into the basis of allergy is urgently needed to underpin further public health policies to address the rise the allergies. – Large, tertiary centres led by allergists should be developed to ensure optimal treatment of patients with complex and severe disease and also as sources for education and training for other clinicians.	– Improved education of medical practitioners to diagnose and treat occupational allergies needed – Improve undergraduate and PCP allergy training – New centres should build on existing excellence – Some specialist services can be restricted to few centres across the country – Educators and Commissioners should work together to develop generic quality assured clinical post graduate allergy courses – NICE to appraise immunotherapy and cost effectiveness – A lead health authority should be identified by the Department of Health in order to establish a pilot tertiary allergy centre. A full cost analysis should be integral to its establishment.	– This report was published by the allergy sub-committee UK House of Lords Science and Technology Committee 2007 – Recommendations made for non-NHS management of allergies (e.g. training teachers in managing allergic emergencies, supporting children with hay fever during school examinations, helping those with occupational allergies return to work, improving allergen food labelling etc) – Authors visited numerous national and international allergy centres of repute to compile this report.
Department of Health (2007)(42)	UK	Report from a publicly funded organisation	Response to the report from the House of Lords Science and Technology Committee 2007	✓	✓	– No published whole system models of services for people with allergy – No data on existing skills – There are also no analyses of effects of active demand management of patient flows in allergy care. – No data on allergy needs in various regions across the country	– The royal colleges should work together to set up curricula for health professional training in allergy. – Health commissioners should work with local service providers to ensure best possible service planning for their catchment areas. – Much clearer understanding of skills and competencies of the existing workforce needed – NICE advised to provide guidance on allergen immunotherapy.	– Funding identified for an allergy centre in the North West region of England. – Most of the recommendations from the House of Lords report could not be acted upon due to insufficient and unreliable data on the existing state of allergy management, according to this report.

Author, (Year) (Ref)	Region	Type of study	Study Aim	Level		Salient Findings	Key Recommendations	Comments
				1^0	2^0			
Warner, JO (2006)(3)	World-wide	Cross-section; Questionnaire survey	To define the current state of allergy training and services in the countries represented within the World Allergy Organisation (WAO)		✓	– Prevalence rates for allergies in the responding countries ranged from 7.5% to 40% (mean 22%) – Number of certified allergists varied widely from 1:25 million in Indonesia to 1:16,000 in Germany. – Formal certification procedure is not available for clinicians in some of the countries surveyed – In most countries, patients are first referred to organ based specialists before being referred to allergists	– There is a very wide gap between demand and provision of allergy services worldwide – Training of medical students, primary care physicians, generalists as well as system specialists who deal with allergy must improve to ensure better care provision – More tertiary level centres needed to set the standards, advance research, support training and provide expertise to primary and secondary care.	– Survey sent to all WAO national society member organisations to be completed by allergists knowledgeable about services within their own countries (61 sent, 34 responses received) – Data based on impressions of these experts in some countries rather than on published data
Department of Health (2006) (43)	UK	Report from a publicly funded organisation	Review of allergy services undertaken to fulfil Government of UK's commitment to the House of Commons Health Committee.	✓	✓	– No compelling evidence on need or on quality of allergy services since relevant research lacking – Patients feel let down by a poor and often inaccessible service – Specialist services are usually not available, resulting in very long waits to see consultants where services do exist – Self-care can be particularly useful in allergy and should be promoted – Some conflict between the main two specialities offering allergy services in the UK (i.e. allergy and clinical immunology)	– Local commissioners need to establish levels of need for services for allergy in their health community – Educators and Commissioners should work together to create additional training spaces for doctors – Guidelines for management and care pathways should be developed by NICE	– Data obtained by review of existing literature and also by interviewing stakeholders – Highlights the difficulties in developing national strategy for allergy services without baseline data on needs and costs involved. – It is important to understand the skills and competencies that exist and those that are needed from the diverse workforce to enable future development and provision of services
El-Shanawany (2005)(52)	UK	Cross-section; Questionnaire survey	To survey allergy services provided by clinical immunologists in the UK		✓	– Immunology centres are the only providers of tertiary allergy care for most of the UK. – Consultant immunologists are likely to be providers of tertiary level allergy care in the medium and long term for the UK – Waiting times for allergy patients in these clinics were long, sometimes waiting over a year for urgent appointments. – Very few centres benefitted from dietician support	– There needs to be a collaborative effort between clinical immunologists and allergists in the UK in order to improve services	– Questionnaires sent via three supra-regional immunology audit groups to the various participating immunology regional centres in the country – 17 immunology centres serving a total population of 32 million individuals responded

Author, (Year) (Ref)	Region	Type of study	Study Aim	Level 1⁰	Level 2⁰	Salient Findings	Key Recommendations	Comments
Ryan, D (2005)(46)	UK	Discussion	To propose minimum levels of knowledge required for clinicians in order to improve standards of allergy care	✓	✓	– Self-care in allergy is problematic due to the poor access to NHS healthcare and the availability of unregulated alternate practitioners. – PCPs and practice nurses could be better trained in prescribing drugs for allergy	– Intermediate care services (eg. PCP with special interest) should be developed – Pharmacists, Primary care nurses and physicians could be trained in a few allergy related techniques to vastly improve service provision	– The authors suggest that management of allergy in primary care can be improved even when specific tests and other infrastructure are unavailable. – Knowledge of pharmacotherapy for allergy can help PCPs manage a majority of patients.
Department of Health (2005)(41)	UK	Report from a publicly funded organisation	Government of UK response to the House of Commons Health Committee report	✓	✓	– Good quality data on needs and services for allergy is lacking – Service models for managing allergy in primary and secondary care could be developed – Medical regulatory bodies overseeing physician and nurse training should be encouraged to increase allergy educational content during training	– Self-care should be encouraged; NHS led expert patient programme will be extended to allergy – Food Standards Agency has produced a guide for those recently diagnosed with food allergies – Local commissioners should establish need for services in their local area	– It was felt that a review of available data and research on allergic conditions is necessary in order to plan future direction of allergy services. This formed the basis for a separate report (as above)
Levy, ML (2004)(45)	UK	Cross-section; Questionnaire survey	Understanding the views of PCPs in the UK regarding the quality of primary and secondary care for allergy	✓		– More than 80% felt that the NHS allergy care was poor – Both primary and secondary care services were thought to be deficient – Very few (4%) offered skin prick tests at their practice – Most expressed concern regarding managing children with allergies – A majority were confident in the management of urticaria, allergic rhinitis, angioedema, anaphylaxis	– National education programmes should be developed for PCPs – Specialist care provision for allergy should be reviewed urgently within the NHS	– Randomly selected sample of 500 PCPs from UK General Practice register were contacted – Only 50% response rate

Author, (Year) (Ref)	Region	Type of study	Study Aim	Level 1⁰	Level 2⁰	Salient Findings	Key Recommendations	Comments
House of Commons Health Committee (2004)(19)	UK	Report from a publicly funded organisation	To highlight the need for allergy service improvement in the UK	✓	✓	– Primary care skill base for allergy is poor- this is compounded by weakness in secondary care sector as well. – Current provision is manifestly inequitable and more allergy specialist centres are required – Better secondary care can help improve primary care knowledge and services – Paediatric service provision worse than that of adults- school nurse training, transition services, dietary recommendations etc all need improving- specialist services can help improve school staff training in allergy by taking on leadership for this. – Poor and sometimes dangerous practice exists in the independent sector. – Data on waiting times are flawed and this adversely affects service planning.	– Allergy specialist centres need to be developed manned by allergists; Allergists cannot be substituted effectively by other specialists – Advocated the establishment of national primary care allergy network. – Ongoing training for allergy in primary care needs to improve; services should be peer reviewed – Introduction of clinical quality markers for allergy to incentivise improvement advised – PCP curriculum needs to be modified to include more allergy – Separate coding for allergy needs to be introduced (now available) – Investment in allergy training required –	– Health committee comprising of elected representatives – Expert interviews, Statistics from published sources, submissions to panels from individuals – patients or carers (300 letters) were all used.
Royal College of Physicians (2003)(20)	UK	Report from a publicly funded organisation	To ensure that allergy services are prioritised for improvement by commissioners and managers in the NHS	✓	✓	– Allergy incidence and prevalence is increasing but services are quite poor. – Very few allergy specialists in the country and few trainees in the pipeline – Primary care physicians not trained to cope with the increasing demands for allergy treatment, most do not feel confident about services, but very few patients are referred to specialists, nonetheless – Few centres offer secondary care allergy; 6 centres UK wide offering tertiary care. Hence PCPs not sure who to refer patients to. – Increasing emergency admissions for allergy – Some papers quoted to suggest specialist services may be cost effective	– Need to have increased allergy specialists (rather than other specialists who are untrained in allergy) – Important to develop regional allergy centres that can help with education, training and networking between primary and secondary care in the region ('Hub and spoke' configuration). – More doctors should be trained to become allergy specialists. – 40 new training posts in allergy will be required. – Patient groups and charities must become more active and lobby for better services – There is a need for more dieticians and nurse specialists in allergy	– Working party consisting of clinical experts from all over the UK, patient representative – Selected publications reviewed (non-systematic) – Other interested stakeholders interviewed, including clinicians, charities supporting patients with allergy, individual patients – Two parts to the report – one covering allergy services and recommendations for improvements and the other covering common allergic conditions and their management.

Author, (Year) (Ref)	Region	Type of study	Study Aim	Level		Salient Findings	Key Recommendations	Comments
				1^0	2^0			
Ewan, PW (2002)(33)	UK	Discussion	Proposal to improve NHS allergy care in the UK		✓	– NHS allergy service provision is inadequate and inequitable – Estimate that there is one whole time equivalent allergist per 3.4 million population in the UK – Only 6 clinics in the UK offer services of full time NHS allergists	– Each of the health areas in the UK should have a regional specialist centre to provide clinical expertise and training – More training posts in allergy should be created	– Data derived from the British Society of Allergy and Clinical Immunology (BSACI) and British Allergy Foundation (BAF) database – Authors assume that part-time allergists provide 0.3 WholeTime Equivalent (WTE) and other specialists provide 0.1 WTE allergy work per week. This is debatable.
Ewan, PW (2000)(53)	UK	Discussion	An overview of NHS allergy services and suggestions for improvement		✓	– There are serious deficiencies in the allergy services within the UK – Training numbers for allergy are not adequate to serve current and future demands on the speciality – Organ specialists (including immunologists) not appropriately trained for the holistic management of these patients	– Minimum of 1 regional allergy centre per region needed manned by allergy specialists and nurses, dietician – Organ based specialists and allergists need to be appointed to more secondary level centres – There should be an increase in specialist training spaces for allergy	– Data from BSACI and BAF database as above – Recommendations as per the Allergy task force set up by the BSACI and DoH in 1998
Brydon, M (1993)(48)	UK	Questionnaire; retrospective	A survey to determine the effectiveness of a nurse practitioner service	✓		– Nurse led service resulted in fewer general practitioner consultations and also a reduction in prescribed medication for allergy – Most respondents reported an improvement in symptoms – Better results seen in patients who were followed up for longer	– Using nurse led services in primary care can be cost saving. – There could have been a recruitment bias/ criteria for choosing a section of patients not made explicit	– Bespoke postal questionnaire before and 9 months after appointment with the nurse – Responses compared with patient notes from PCP

Abbreviations:

PCP: Primary Care Physician; EAACI: European Academy of Allergy and Clinical Immunology; DoH: Department of Health (UK); NHS: National Health Service (UK); NICE: National Institute of Health and Care Excellence, UK; PROM: Patient Reported Outcome Measures; MCN: Managed Clinical Network;
WAO: World Allergy Organisation; BSACI: British Society of Allergy and Clinical Immunology; BAF: British Allergy Foundation;
Level: 1^0 (primary)- refers to care delivered by primary care physicians, nurses and other practitioners who are non-specialist and offer services in the home or community.
2^0 (secondary) services refer to those provided in hospitals by clinicians (doctors or nurses) deemed to have specialist training and knowledge relevant to the management of the condition

3.A: SOME OF THE ROUTINELY COLLECTED HEALTH/ POPULATION DATASETS AVAILABLE IN THE UK

NAME OF DATABASE	DESCRIPTION	LEVEL	REGION
The Health Improvement Network (THIN)	Managed by IMS Real World Evidence; Anonymised longitudinal database of routine primary care visits; Vision software	Primary care	UK
RCGP weekly returns service	Weekly consultations for selected conditions from 100 GP practices	Primary care	England and Wales
GP Research Database	Run by the MHRA; Anonymised longitudinal database of 1^{0} care records; Vision software	Primary care	UK
Doctors Independent Network (DIN)	Direct download of normal working activity of about 1500 GPs from over 350 General Practices	Primary care	UK
Q-Research	Run by Nottingham University; 655 general practices with 13 million registered patients; EMIS software	Primary care	UK
Prescription cost Analysis (PCA)	Based on data sent to the prescription pricing authority for payment; Only those dispensed in community (not hospital/ private)	Secondary care	England
Hospital Episode Statistics (HES)	Personal , medical and administrative details of all patients admitted to and treated in NHS hospitals	Secondary care	England
Office of National Statistics (ONS)	Key economic and social indicators; Data is free; Includes longitudinal study for England and Wales	General Population	UK

3.B: MAIN DIFFERENCES BETWEEN THIN AND HES DATABASES

FEATURE	THIN	HES
Type of data	Primary care data; Produced when health care is demanded (i.e. when a person consults his/ her primary care physician)	Secondary care data; Produced when health care is provided at secondary care level
Data content	About 6% of UK general population is represented in the THIN database. Data is longitudinally collected (see Fig.3.1) and has recently been linked to HES.	NHS secondary care admission data from all of England is included. Data is presented as episodes. Longitudinal data is not available.
Geographical area	All of UK; Currently over 500 practices in UK and over 40 in W.Midlands contribute to the dataset	Only English NHS hospitals contribute to the data.
Data inception and updating	Database started in January 2003, although records are available from 1994. Data are updated throughout the year (usually once every 3 months).	Database started in 1987; Admitted patient care data available since 1989-90; Data are updated monthly
Coding system	Read codes, Version 2.0	ICD-10
Data managed by	IMS Health Real World Evidence; Vision software installed in the participating GP surgeries and data regularly gathered.	Managed by Secondary User Service (SUS) under the auspices of the Health and Social care Information centre (HSCIC).
Deprivation index	Townsend score	Index of multiple deprivation (IMD) scores

3.C: CONDITIONS CONSIDERED IN THE THIN DATABASE ANALYSIS

CONDITION	DESCRIPTION
Allergy	An exaggerated, abnormal immune reaction to a normally harmless substance. Symptoms can range between mild rash, itchiness in mouth and throat, hives (urticaria) after ingestion of the allergen to a potentially life threatening reaction called anaphylaxis.
Allergen	A substance that induces an allergic reaction
Allergic rhinitis (AR)	Allergic rhinitis is an inflammation of the inside of the nose caused by an allergen, such as pollen, dust, mould or flakes of skin from certain animals. Symptoms include sneezing, runny and /or itchy nose, blocked nose. AR can present during certain times of the year (seasonal AR) or throughout the year (perennial AR)
Allergic conjunctivitis	Allergic conjunctivitis is a condition wherein an allergen that causes redness and inflammation of the thin layer of tissue that covers the front of the eye (the conjunctiva). Symptoms include red, itchy, watery (or sometimes dry) eyes. It is usually associated with allergic rhinitis and may be seasonal or perennial
Allergic rhinoconjunctivitis	A combination of allergic rhinitis and conjunctivitis. This condition can be seasonal or perennial.
Food Allergy	The allergen in this case is a protein related to food. Food allergy is the commonest cause for anaphylaxis is childhood.
Nut allergy	Allergy to one or more nuts. Commonest nut allergen for children in the UK is peanut, although tree nut allergy (cashew, almonds, walnuts, macademia, brazil nuts etc) is also seen. Only 20% of children outgrow nut allergy by age 7.
Egg allergy	It is a common food allergy in young children. However, about 80% outgrow egg allergy by age 5.
Urticaria	It is a raised, itchy rash that appears on the skin. It is usually described as hives, wheals, welts or nettle rash. It can occur in susceptible individuals as a result of an allergic reaction (e.g. food allergy), during infections, exposure to certain physical stimuli (e.g. heat/cold), or may occur without

	an obvious cause
Eczema/ Atopic dermatitis	Atopic dermatitis is the most common type of eczema. It is a chronic condition seen in association with allergies in children (and also adults), although it is not usually a manifestation of allergy *per se*. Eczematous skin is usually red, itchy, dry and cracked. The condition is characterised by periods of remission and flare-ups.
Allergic asthma	Asthma is a common long-term condition that can cause coughing, wheezing, chest tightness and breathlessness. In many cases, especially in children, asthma is caused due to allergies. Symptoms of allergic and non-allergic asthma are the same.
Complex allergies	The diagnosis of more than one allergy (or related condition) in a given individual. For example, individuals who have been diagnosed with a combination of allergic rhinoconjunctivitis (or food allergy), asthma and eczema.

3.D: READ CODES USED IN THE ANALYSIS

READCODE	DESCRIPTION	SUBGROUP
All Asthma		
173A.00	Exercise induced asthma	Asthma
1781	Asthma trigger - pollen	Asthma
1787	Asthma trigger - seasonal	Asthma
1O2..00	Asthma confirmed	Asthma
H312000	Chronic asthmatic bronchitis	Asthma
H33..00	Asthma	Asthma
H33..11	Bronchial asthma	Asthma
H330.00	Extrinsic (atopic) asthma	Asthma
H330.11	Allergic asthma	Asthma
H330.12	Childhood asthma	Asthma
H330.13	Hay fever with asthma	Asthma
H330.14	Pollen asthma	Asthma
H330000	Extrinsic asthma without status asthmaticus	Asthma
H330011	Hay fever with asthma	Asthma
H330100	Extrinsic asthma with status asthmaticus	Asthma
H330111	Extrinsic asthma with asthma attack	Asthma
H330z00	Extrinsic asthma NOS	Asthma
H331.00	Intrinsic asthma	Asthma
H331.11	Late onset asthma	Asthma
H331000	Intrinsic asthma without status asthmaticus	Asthma
H331100	Intrinsic asthma with status asthmaticus	Asthma
H331111	Intrinsic asthma with asthma attack	Asthma
H331z00	Intrinsic asthma NOS	Asthma
H332.00	Mixed asthma	Asthma
H333.00	Acute exacerbation of asthma	Asthma
H334.00	Brittle asthma	Asthma
H335.00	Chronic asthma with fixed airflow obstruction	Asthma
H33z.00	Asthma unspecified	Asthma
H33z.11	Hyperreactive airways disease	Asthma
H33z000	Status asthmaticus NOS	Asthma
H33z011	Severe asthma attack	Asthma
H33z100	Asthma attack	Asthma
H33z111	Asthma attack NOS	Asthma
H33z200	Late-onset asthma	Asthma
H33zz00	Asthma NOS	Asthma
H33zz11	Exercise induced asthma	Asthma
H33zz12	Allergic asthma NEC	Asthma
H33zz13	Allergic bronchitis NEC	Asthma
H35y600	Sequoiosis (red-cedar asthma)	Asthma
H35y700	Wood asthma	Asthma
H47y000	Detergent asthma	Asthma
173c.00	Occupational asthma	Asthma
173d.00	Work aggravated asthma	Asthma
Allergic Rhinoconjunctivitis (ARC)		
F4A3100	Vernal conjunctivitis of limbus and cornea	Allergic conjunctivitis
F4C0600	Acute atopic conjunctivitis	Allergic conjunctivitis
F4C0611	Acute allergic conjunctivitis	Allergic conjunctivitis
F4C1300	Vernal conjunctivitis	Allergic conjunctivitis

F4C1400	Other chronic allergic conjunctivitis	Allergic conjunctivitis
F4C1411	Allergic conjunctivitis	Allergic conjunctivitis
H17..00	Allergic rhinitis	Allergic rhinitis
H17..11	Perennial rhinitis	Allergic rhinitis
H17..12	Allergic rhinosinusitis	Allergic rhinitis
H171.00	Allergic rhinitis due to other allergens	Allergic rhinitis
H172.00	Allergic rhinitis due to unspecified allergen	Allergic rhinitis
H17z.00	Allergic rhinitis NOS	Allergic rhinitis
Hyu2100	[X]Other allergic rhinitis	Allergic rhinitis
H171.11	Cat allergy	Allergic rhinitis
H171.12	Dander (animal) allergy	Allergic rhinitis
H171.13	Feather allergy	Allergic rhinitis
H171000	Allergy to animal	Allergic rhinitis
H171100	Dog allergy	Allergic rhinitis
H171.15	House dust allergy	Allergic rhinitis
H171.16	House dust mite allergy	Allergic rhinitis
H170.00	Allergic rhinitis due to pollens	Hay fever
H170.11	Hay fever - pollens	Hay fever
H171.14	Hay fever - other allergen	Hay fever
H172.11	Hay fever - unspecified allergen	Hay fever
Hyu2000	[X]Other seasonal allergic rhinitis	Hay fever
SN5A.00	Oral allergy syndrome	Hay fever
Anaphylaxis		
SN50.00	Anaphylactic shock	Anaphylaxis
SN50000	Anaphylactic shock due to adverse food reaction	Anaphylaxis
SN50100	Anaphy shock due/adv efect/correct drug or med proprly admin	Anaphylaxis
SN51.00	Angioneurotic oedema	Angioedema
SN51.11	Angioedema	Angioedema
M102.00	Infectious eczematoid dermatitis	Eczema-like
M125.00	Contact dermatitis due to food in contact with skin	Eczema-like
M125z00	Contact dermatitis due to food NOS	Eczema-like
M128500	Allergic contact dermatitis due to food in contact with skin	Eczema-like
M183100	Neurodermatitis circumscripta	Eczema-like
SN52.00	Drug hypersensitivity NOS	Drug allergy
SN52.11	Adverse drug reaction NOS	Drug allergy
SN52.13	Drug idiosyncrasy NOS	Drug allergy
Eczema		
26C4.00	Nipple eczema	Eczema
F4D3000	Eczematous eyelid dermatitis	Eczema
F4D3112	Contact eczema - eyelids	Eczema
F502400	Acute eczematoid otitis externa	Eczema
F502411	Eczema of external ear	Eczema
M07y.11	Pustular eczema	Eczema
M102.11	Pustular eczema	Eczema
M11..00	Atopic dermatitis and related conditions	Eczema
M111.00	Atopic dermatitis/eczema	Eczema
M112.00	Infantile eczema	Eczema
M113.00	Flexural eczema	Eczema
M114.00	Allergic (intrinsic) eczema	Eczema
M119.00	Discoid eczema	Eczema
M11A.00	Asteatotic eczema	Eczema
M11z.00	Atopic dermatitis NOS	Eczema

M12..00	Contact dermatitis and other eczemas	Eczema
M12..12	Contact eczema	Eczema
M12z100	Eczema NOS	Eczema
M12z111	Discoid eczema	Eczema
M12z200	Infected eczema	Eczema
M12z300	Hand eczema	Eczema
M12z400	Erythrodermic eczema	Eczema
Myu2.00	[X]Dermatitis and eczema	Eczema
Myu2200	[X]Exacerbation of eczema	Eczema
Eczema-like		
F4D3100	Contact or allergic eyelid dermatitis	Dermatitis
F4D3111	Allergic dermatitis - eyelid	Dermatitis
F4D4.00	Infective eyelid dermatitis of types resulting in deformity	Dermatitis
F4D5.00	Other eyelid infective dermatitis	Dermatitis
M070.11	Purulent dermatitis	Dermatitis
M07z.14	Infected dermatitis	Dermatitis
M1...11	Dermatitis/dermatoses	Dermatitis
M101.00	Seborrhoeic dermatitis	Dermatitis
M101.11	Seborrhoeic dermatitis capitis	Dermatitis
M101.12	Seborrhoeic eczema	Dermatitis
M110.00	Napkin dermatitis	Dermatitis
M110.11	Ammonia dermatitis	Dermatitis
M118.00	Infantile seborrhoeic dermatitis	Dermatitis
M118000	Infantile seborrhoeic dermatitis capitis	Dermatitis
M118z00	Infantile seborrhoeic dermatitis NOS	Dermatitis
M12..11	Contact dermatitis	Dermatitis
M12..13	Occupational dermatitis	Dermatitis
M120.00	Contact dermatitis due to detergents	Dermatitis
M121.00	Contact dermatitis due to oils and greases	Dermatitis
M121.11	Grease contact dermatitis	Dermatitis
M121.12	Oil contact dermatitis	Dermatitis
M122.00	Contact dermatitis due to solvents	Dermatitis
M122000	Contact dermatitis due to chlorocompound	Dermatitis
M122100	Contact dermatitis due to cyclohexane	Dermatitis
M122200	Contact dermatitis due to ester	Dermatitis
M122300	Contact dermatitis due to glycol	Dermatitis
M122400	Contact dermatitis due to hydrocarbon	Dermatitis
M122500	Contact dermatitis due to ketone	Dermatitis
M122z00	Contact dermatitis due to solvent NOS	Dermatitis
M123.00	Contact dermatitis due to drugs and medicaments	Dermatitis
M123000	Contact dermatitis due to arnica	Dermatitis
M123100	Contact dermatitis due to fungicides	Dermatitis
M123200	Contact dermatitis due to iodine	Dermatitis
M123300	Contact dermatitis due to keratolytics	Dermatitis
M123400	Contact dermatitis due to mercurials	Dermatitis
M123500	Contact dermatitis due to neomycin	Dermatitis
M123600	Contact dermatitis due to pediculocides	Dermatitis
M123700	Contact dermatitis due to phenols	Dermatitis
M123800	Contact dermatitis due to scabicides	Dermatitis
M123z00	Contact dermatitis due to medicament NOS	Dermatitis
M124.00	Contact dermatitis due to other chemical products	Dermatitis
M124000	Contact dermatitis due to acids	Dermatitis

M124100	Contact dermatitis due to adhesive plaster	Dermatitis
M124111	Elastoplast contact dermatitis	Dermatitis
M124200	Contact dermatitis due to alkalis	Dermatitis
M124300	Contact dermatitis due to caustics	Dermatitis
M124400	Contact dermatitis due to dichromate	Dermatitis
M124500	Contact dermatitis due to insecticide	Dermatitis
M124600	Contact dermatitis due to nylon	Dermatitis
M124700	Contact dermatitis due to plastic	Dermatitis
M124800	Contact dermatitis due to rubber	Dermatitis
M124z00	Contact dermatitis: other chemicals NOS	Dermatitis
M125000	Contact dermatitis due to cereals	Dermatitis
M125100	Contact dermatitis due to fish	Dermatitis
M125200	Contact dermatitis due to flour	Dermatitis
M125300	Contact dermatitis due to fruit	Dermatitis
M125400	Contact dermatitis due to meat	Dermatitis
M125500	Contact dermatitis due to milk	Dermatitis
M125z11	Egg contact dermatitis	Dermatitis
M126.00	Contact dermatitis due to plants	Dermatitis
M126000	Contact dermatitis due to lacquer tree	Dermatitis
M126100	Contact dermatitis due to poison-ivy	Dermatitis
M126200	Contact dermatitis due to poison-oak	Dermatitis
M126300	Contact dermatitis due to poison-sumac	Dermatitis
M126400	Contact dermatitis due to poison-vine	Dermatitis
M126500	Contact dermatitis due to primrose	Dermatitis
M126600	Contact dermatitis due to ragweed	Dermatitis
M126z00	Contact dermatitis due to plants NOS	Dermatitis
M127.00	Contact dermatitis due to solar radiation	Dermatitis
M127000	Unspecified contact dermatitis due to solar radiation	Dermatitis
M127300	Photodermatitis	Dermatitis
M127800	Photocontact dermatitis [berloque dermatitis]	Dermatitis
M127z00	Contact dermatitis due to solar radn NOS	Dermatitis
M128.00	Allergic contact dermatitis	Dermatitis
M128000	Allergic contact dermatitis due to adhesives	Dermatitis
M128100	Allergic contact dermatitis due to cosmetics	Dermatitis
M128200	Allergic contact dermatitis due drugs in contact with skin	Dermatitis
M128300	Allergic contact dermatitis due to dyes	Dermatitis
M128400	Allergic contact dermatitis due to other chemical products	Dermatitis
M128600	Allergic contact dermatitis due to plants, except food	Dermatitis
M129.00	Irritant contact dermatitis	Dermatitis
M129000	Irritant contact dermatitis due to cosmetics	Dermatitis
M129100	Irritant contact dermatitis due drugs in contact with skin	Dermatitis
M129200	Irritant contact dermatitis due to other chemical products	Dermatitis
M129300	Irritant contact dermatitis due to food in contact with skin	Dermatitis
M129400	Irritant contact dermatitis due to plants, except food	Dermatitis
M129500	Incontinence-associated dermatitis	Dermatitis
M12C.00	Radiodermatitis	Dermatitis
M12C000	Acute radiodermatitis	Dermatitis
M12C100	Chronic radiodermatitis	Dermatitis
M12y.00	Contact dermatitis due to other specified agents	Dermatitis
M12y000	Contact dermatitis due to cosmetics	Dermatitis
M12y011	Lanolin contact dermatitis	Dermatitis
M12y012	Perfume contact dermatitis	Dermatitis

M12y100	Contact dermatitis due to cold weather	Dermatitis
M12y200	Contact dermatitis due to dyes	Dermatitis
M12y300	Contact dermatitis due to furs	Dermatitis
M12y400	Contact dermatitis due to hot weather	Dermatitis
M12y500	Contact dermatitis due to infra-red rays	Dermatitis
M12y600	Contact dermatitis due to jewellery	Dermatitis
M12y700	Contact dermatitis due to light (excluding sunlight)	Dermatitis
M12y800	Contact dermatitis due to metals	Dermatitis
M12y900	Contact dermatitis due to preservatives	Dermatitis
M12yA00	Contact dermatitis due to radiation NOS	Dermatitis
M12yB00	Contact dermatitis due to ultra-violet rays (excluding sun)	Dermatitis
M12yC00	Contact dermatitis due to x-rays	Dermatitis
M12yD00	Contact dermatitis due to casting materials	Dermatitis
M12yz00	Contact dermatitis: specified agent NOS	Dermatitis
M12z.00	Contact dermatitis NOS	Dermatitis
M12z000	Dermatitis NOS	Dermatitis
M12zz00	Contact dermatitis NOS	Dermatitis
M13..00	Ingestion dermatitis	Dermatitis
M130.00	Ingestion dermatitis due to drugs	Dermatitis
M131.00	Ingestion dermatitis due to food	Dermatitis
M13y.00	Ingestion dermatitis due to other specified substance	Dermatitis
M13z.00	Ingestion dermatitis NOS	Dermatitis
M153500	Perioral dermatitis	Dermatitis
M153511	Circumoral dermatitis	Dermatitis
M153600	Periocular dermatitis	Dermatitis
M15y011	Dermatitis exfoliativa neonatorum	Dermatitis
M17y200	Infantile papular acrodermatitis	Dermatitis
M184.00	Dermatitis artefacta	Dermatitis
M184.11	Dermatitis factitia	Dermatitis
M1B..11	Juvenile plantar dermatitis	Dermatitis
M1y0.00	Nummular dermatitis	Dermatitis
M2y4811	Juvenile plantar dermatitis	Dermatitis
Myu2000	[X]Other seborrhoeic dermatitis	Dermatitis
Myu2100	[X]Allergic contact dermatitis due to oth chemical products	Dermatitis
Myu2300	[X]Allergic contact dermatitis due to other agents	Dermatitis
Myu2400	[X]Irritant contact dermatitis due to oth chemical products	Dermatitis
Myu2500	[X]Irritant contact dermatitis due to other agents	Dermatitis
Myu2600	[X]Unspcfd contact dermatitis due to other chemical products	Dermatitis
Myu2700	[X]Unspecified contact dermatitis due to other agents	Dermatitis
Myu2800	[X]Dermatitis due to other substances taken internally	Dermatitis
Myu2900	[X]Dermatitis due to unspecified substance taken internally	Dermatitis
Myu2C00	[X]Other specified dermatitis	Dermatitis
1N03.00	C/O: dry skin	Dry skin
2587.00	O/E - abd.skin dry-dehydration	Dry skin
2587.12	O/E - abdominal skin dry	Dry skin
2F13.00	O/E - dry skin	Dry skin
M116.00	Neurodermatitis - diffuse	Dry skin
M116.11	Brocq's neurodermatitis	Dry skin
M117.00	Neurodermatitis - atopic	Dry skin
Z1O1300	Drying skin creases	Dry skin
Food allergy		
13A7.00	Egg free diet - allergy	Egg allergy

SN58000	Egg allergy	Egg allergy
SN58100	Egg protein allergy	Egg allergy
SN58200	Peanut allergy	Nut allergy
SN58300	Nut allergy	Nut allergy
ZC21L00	Advice to avoid nut intake	Nut allergy
13A6.00	Milk free diet - allergy	Other food allergy
8CA4S00	Dietary education for food allergy	Other food allergy
8CA4S11	Dietary advice for food allergy	Other food allergy
J154000	Allergic gastritis	Other food allergy
J432.00	Allergic gastroenteritis and colitis	Other food allergy
J432.11	Allergic diarrhoea	Other food allergy
J432.12	Cow's milk allergy	Other food allergy
J432000	Allergic gastroenteritis	Other food allergy
J432100	Allergic enteritis	Other food allergy
J432200	Allergic enterocolitis	Other food allergy
J432300	Allergic colitis	Other food allergy
J432z00	Allergic gastroenteritis NOS	Other food allergy
SN58.00	Food allergy	Other food allergy
SN58400	Wheat allergy	Other food allergy
SN58800	Mushroom allergy	Other food allergy
SN58900	Allergy to strawberries	Other food allergy
SN58911	Strawberry allergy	Other food allergy
SN58A00	Allergy to soya	Other food allergy
ZC2CF00	Dietary advice for food allergy	Other food allergy
SN58500	Fish allergy	Seafood allergy
SN58600	Seafood allergy	Seafood allergy
SN58700	Shellfish allergy	Seafood allergy
Other allergies		
SN53.11	Hypersensitivity NOS	Other allegies
SN52.12	Allergic drug reaction NOS	Other allergies
SN53.00	Allergy, unspecified	Other allergies
SN53000	Allergic reaction	Other allergies
SN53100	Latex allergy	Other allergies
SN53200	Allergic reaction to tattoo ink	Other allergies
D403300	Allergic eosinophilia	Other allergies
F510400	Acute allergic serous otitis media	Other allergies
F510500	Acute allergic mucoid otitis media	Other allergies
F510600	Acute allergic sanguinous otitis media	Other allergies
F513000	Chronic allergic otitis media	Other allergies
F514000	Allergic otitis media NOS	Other allergies
H025.00	Allergic pharyngitis	Other allergies
J072000	Allergic parotitis	Other allergies
N062.00	Allergic arthritis	Other allergies
N062000	Allergic arthritis of unspecified site	Other allergies
N062100	Allergic arthritis of the shoulder region	Other allergies
N062200	Allergic arthritis of the upper arm	Other allergies
N062300	Allergic arthritis of the forearm	Other allergies
N062400	Allergic arthritis of the hand	Other allergies
N062500	Allergic arthritis of the pelvic region and thigh	Other allergies
N062600	Allergic arthritis of the lower leg	Other allergies
N062700	Allergic arthritis of the ankle and foot	Other allergies
N062800	Allergic arthritis of other specified site	Other allergies

N062900	Allergic arthritis of multiple sites	Other allergies
N062z00	Allergic arthritis NOS	Other allergies
SN59.00	Allergic reaction to venom	Venom allergy
SN59000	Allergic reaction to bee sting	Venom allergy
SN59100	Allergic reaction to insect bite	Venom allergy
SN59200	Allergic reaction to wasp sting	Venom allergy
SN59300	Anaphylactic shock due to bee sting	Venom allergy
SN59400	Anaphylactic shock due to wasp sting	Venom allergy
Referral		
ZLE6100	Discharge from clinical allergy service	Referral allergy
8HVK000	Private referral to allergy specialist	Referral allergy
8Hld.00	Referral to clinical allergy service	Referral allergy
8T0C.00	Referral to paediatric allergy service	Referral allergy
9NlX.00	Seen by clinical allergy - service	Referral allergy
ZL18200	Under care of clinical allergist	Referral allergy
ZL5A600	Referral to clinical allergist	Referral allergy
ZL9A200	Seen by clinical allergist	Referral allergy
ZLD3200	Discharge by clinical allergist	Referral allergy
8HTu.00	Referral to eczema clinic	Referral eczema
2126200	Asthma resolved	Asthma resolved
212G.00	Asthma resolved	Asthma resolved
Urticaria		
M28..00	Urticaria	urticaria
M280.00	Allergic urticaria	urticaria
M280.11	Drug induced urticaria	urticaria
M281.00	Idiopathic urticaria	urticaria
M282.00	Urticaria due to cold and heat	urticaria
M282000	Cold urticaria	urticaria
M282100	Thermal urticaria	urticaria
M282111	Heat urticaria	urticaria
M282z00	Urticaria due to cold and heat NOS	urticaria
M283.00	Dermatographic urticaria	urticaria
M283.11	Factitial urticaria	urticaria
M284.00	Vibratory urticaria	urticaria
M285.00	Cholinergic urticaria	urticaria
M286.00	Contact urticaria	urticaria
M287.00	Physical urticaria	urticaria
M28y.00	Other specified urticaria	urticaria
M28y.11	Nettle rash	urticaria
M28y000	Urticaria geographica	urticaria
M28y100	Menstrual urticaria	urticaria
M28y200	Urticaria persistans	urticaria
M28yz00	Other specified urticaria NOS	urticaria
M28z.00	Urticaria NOS	urticaria
M28z.11	Hives	urticaria
Myu4.00	[X]Urticaria and erythema	urticaria
Myu4000	[X]Other urticaria	urticaria

READCODE	DESCRIPTION	SUBGROUP
Prevalence		
14M4.00	H/O: cat allergy	Allergic rhinitis
14M5.00	H/O: anaphylactic shock	Anaphylaxis
ZV1B300	[V]Personal history of food induced anaphylaxis	Anaphylaxis
14B4.00	H/O: asthma	Asthma
178..00	Asthma trigger	Asthma
1780.00	Aspirin induced asthma	Asthma
1781.00	Asthma trigger - pollen	Asthma
1782.00	Asthma trigger - tobacco smoke	Asthma
1783.00	Asthma trigger - warm air	Asthma
1784.00	Asthma trigger - emotion	Asthma
1785.00	Asthma trigger - damp	Asthma
1786.00	Asthma trigger - animals	Asthma
1787.00	Asthma trigger - seasonal	Asthma
1788.00	Asthma trigger - cold air	Asthma
1789.00	Asthma trigger - respiratory infection	Asthma
178A.00	Asthma trigger - airborne dust	Asthma
178B.00	Asthma trigger - exercise	Asthma
661M100	Asthma self-management plan agreed	Asthma
661N100	Asthma self-management plan review	Asthma
663..11	Asthma monitoring	Asthma
663N.00	Asthma disturbing sleep	Asthma
663N000	Asthma causing night waking	Asthma
663N100	Asthma disturbs sleep weekly	Asthma
663N200	Asthma disturbs sleep frequently	Asthma
663O.00	Asthma not disturbing sleep	Asthma
663O000	Asthma never disturbs sleep	Asthma
663P.00	Asthma limiting activities	Asthma
663P000	Asthma limits activities 1 to 2 times per month	Asthma
663P100	Asthma limits activities 1 to 2 times per week	Asthma
663P200	Asthma limits activities most days	Asthma
663Q.00	Asthma not limiting activities	Asthma
663U.00	Asthma management plan given	Asthma
663V.00	Asthma severity	Asthma
663V000	Occasional asthma	Asthma
663V100	Mild asthma	Asthma
663V200	Moderate asthma	Asthma
663V300	Severe asthma	Asthma
663W.00	Asthma prophylactic medication used	Asthma
663d.00	Emergency asthma admission since last appointment	Asthma
663e.00	Asthma restricts exercise	Asthma
663e000	Asthma sometimes restricts exercise	Asthma
663e100	Asthma severely restricts exercise	Asthma
663f.00	Asthma never restricts exercise	Asthma
663h.00	Asthma - currently dormant	Asthma
663j.00	Asthma - currently active	Asthma
663m.00	Asthma accident and emergency attendance since last visit	Asthma
663n.00	Asthma treatment compliance satisfactory	Asthma
663p.00	Asthma treatment compliance unsatisfactory	Asthma
663q.00	Asthma daytime symptoms	Asthma
663r.00	Asthma causes night symptoms 1 to 2 times per month	Asthma

663s.00	Asthma never causes daytime symptoms	Asthma
663t.00	Asthma causes daytime symptoms 1 to 2 times per month	Asthma
663u.00	Asthma causes daytime symptoms 1 to 2 times per week	Asthma
663v.00	Asthma causes daytime symptoms most days	Asthma
663w.00	Asthma limits walking up hills or stairs	Asthma
663x.00	Asthma limits walking on the flat	Asthma
663y.00	Number of asthma exacerbations in past year	Asthma
66Y5.00	Change in asthma management plan	Asthma
66Y9.00	Step up change in asthma management plan	Asthma
66YA.00	Step down change in asthma management plan	Asthma
66YC.00	Absent from work or school due to asthma	Asthma
66YE.00	Asthma monitoring due	Asthma
66YJ.00	Asthma annual review	Asthma
66YK.00	Asthma follow-up	Asthma
66YP.00	Asthma night-time symptoms	Asthma
66YQ.00	Asthma monitoring by nurse	Asthma
66YR.00	Asthma monitoring by doctor	Asthma
66YZ.00	Does not have asthma management plan	Asthma
66Yp.00	Asthma review using Roy Colleg of Physicians three questions	Asthma
66Yq.00	Asthma causes night time symptoms 1 to 2 times per week	Asthma
66Yr.00	Asthma causes symptoms most nights	Asthma
66Ys.00	Asthma never causes night symptoms	Asthma
66Yu.00	Number days absent from school due to asthma in past 6 month	Asthma
679J.00	Health education - asthma	Asthma
679J000	Health education - asthma self management	Asthma
679J100	Health education - structured asthma discussion	Asthma
679J200	Health education - structured patient focused asthma discuss	Asthma
68C3.00	Asthma screening	Asthma
8791.00	Further asthma - drug prevent.	Asthma
8793.00	Asthma control step 0	Asthma
8794.00	Asthma control step 1	Asthma
8795.00	Asthma control step 2	Asthma
8796.00	Asthma control step 3	Asthma
8797.00	Asthma control step 4	Asthma
8798.00	Asthma control step 5	Asthma
8B3j.00	Asthma medication review	Asthma
8CE2.00	Asthma leaflet given	Asthma
8CMA000	Patient has a written asthma personal action plan	Asthma
8CR0.00	Asthma clinical management plan	Asthma
8H2P.00	Emergency admission, asthma	Asthma
8HTT.00	Referral to asthma clinic	Asthma
9N1d.00	Seen in asthma clinic	Asthma
9N1d000	Seen in school asthma clinic	Asthma
9N4Q.00	DNA - Did not attend asthma clinic	Asthma
9NI8.00	Asthma outreach clinic	Asthma
9NNX.00	Under care of asthma specialist nurse	Asthma
9OJ..00	Asthma monitoring admin.	Asthma
9OJ..11	Asthma clinic administration	Asthma
9OJ1.00	Attends asthma monitoring	Asthma
9OJ2.00	Refuses asthma monitoring	Asthma
9OJ3.00	Asthma monitor offer default	Asthma
9OJ4.00	Asthma monitor 1st letter	Asthma

9OJ5.00	Asthma monitor 2nd letter	Asthma
9OJ6.00	Asthma monitor 3rd letter	Asthma
9OJ7.00	Asthma monitor verbal invite	Asthma
9OJ8.00	Asthma monitor phone invite	Asthma
9OJ9.00	Asthma monitoring deleted	Asthma
9OJA.00	Asthma monitoring check done	Asthma
9OJA.11	Asthma monitored	Asthma
9OJZ.00	Asthma monitoring admin.NOS	Asthma
9hA..00	Exception reporting: asthma quality indicators	Asthma
9hA1.00	Excepted from asthma quality indicators: Patient unsuitable	Asthma
9hA2.00	Excepted from asthma quality indicators: Informed dissent	Asthma
14L..00	H/O: drug allergy	Drug allergy
14L1.00	H/O: penicillin allergy	Drug allergy
14L2.00	H/O: antibiotic allergy NOS	Drug allergy
14L3.00	H/O: anaesthetic allergy	Drug allergy
14L4.00	H/O: analgesic allergy	Drug allergy
14L5.00	H/O: vaccine allergy	Drug allergy
14L5000	H/O: rotavirus vaccine allergy	Drug allergy
14L6.00	H/O: serum allergy	Drug allergy
14L7.00	H/O: cephalosporin allergy	Drug allergy
14L8.00	H/O: tetracycline allergy	Drug allergy
14L9.00	H/O: gentamicin allergy	Drug allergy
14LA.00	H/O: erythromycin allergy	Drug allergy
14LB.00	H/O: neomycin allergy	Drug allergy
14LC.00	H/O: chloramphenicol allergy	Drug allergy
14LD.00	H/O: sulphonamide allergy	Drug allergy
14LE.00	H/O: trimethoprim allergy	Drug allergy
14LF.00	H/O: co-trimoxazole allergy	Drug allergy
14LG.00	H/O: metronidazole allergy	Drug allergy
14LH.00	H/O: nalidixic acid allergy	Drug allergy
14LI.00	H/O: nitrofurantoin allergy	Drug allergy
14LJ.00	H/O: influenza vaccine allergy	Drug allergy
14LK.00	H/O: aspirin allergy	Drug allergy
14LL.00	H/O: betablocker allergy	Drug allergy
14LM.00	H/O: angiotensin converting enzyme inhibitor allergy	Drug allergy
14LN.00	H/O: angiotensin II receptor antagonist allergy	Drug allergy
14LP.00	H/O: warfarin allergy	Drug allergy
14LQ.00	H/O: clopidogrel allergy	Drug allergy
14LR.00	H/O: pneumococcal vaccine allergy	Drug allergy
14LS.00	H/O: combined calcium and vitamin D3 preparation allergy	Drug allergy
14LT.00	H/O: bisphosphonate allergy	Drug allergy
14LT000	H/O ibandronic acid allergy	Drug allergy
14LT100	H/O zoledronic acid monohydrate allergy	Drug allergy
14LT200	H/O disodium etidronate allergy	Drug allergy
14LT300	H/O alendronic acid allergy	Drug allergy
14LT400	H/O risedronate sodium allergy	Drug allergy
14LV.00	H/O: selective oestrogen receptor modulator allergy	Drug allergy
14LW.00	H/O: strontium ranelate allergy	Drug allergy
14LX.00	H/O: dipyridamole allergy	Drug allergy
14LZ.00	H/O: drug allergy NOS	Drug allergy
14La.00	H/O: raloxifene allergy	Drug allergy
14Lb.00	H/O: teriparatide allergy	Drug allergy

14Lc.00	H/O denosumab allergy	Drug allergy
14Ld.00	H/O calcitonin allergy	Drug allergy
ZV14.00	[V]Personal history of drug allergy	Drug allergy
ZV14100	[V]Personal history of other antibiotic allergy	Drug allergy
ZV14200	[V]Personal history of sulphonamide allergy	Drug allergy
ZV14300	[V]Personal history of other anti-infective agent allergy	Drug allergy
ZV14400	[V]Personal history of anaesthetic agent allergy	Drug allergy
ZV14500	[V]Personal history of narcotic agent allergy	Drug allergy
ZV14600	[V]Personal history of analgesic agent allergy	Drug allergy
ZV14700	[V]Personal history of serum or vaccine allergy	Drug allergy
ZV14800	[V]Personal history of aspirin allergy	Drug allergy
ZV14900	[V]Personal history of co-proxamol allergy	Drug allergy
ZV14A00	[V]Personal history of warfarin allergy	Drug allergy
ZV14B00	[V]Personal history of clopidogrel allergy	Drug allergy
ZV14C00	[V]Personal history of betablocker allergy	Drug allergy
ZV14D00	[V]PH angiotensin-converting-enzyme inhibitor allergy	Drug allergy
ZV14E00	[V]PH of angiotensin II receptor antagonist allergy	Drug allergy
ZV14F00	[V]Personal history of influenza vaccine allergy	Drug allergy
ZV14G00	[V]Personal history of pneumococcal vaccine allergy	Drug allergy
ZV14H00	[V]Personal history of strontium ranelate allergy	Drug allergy
ZV14J00	[V]PH of selective oestrogen receptor modulator allergy	Drug allergy
ZV14K00	[V]Personal history of bisphosphonate allergy	Drug allergy
ZV14L00	[V]Personal history of calcium allergy	Drug allergy
ZV14M00	[V]Personal history of vitamin D3 allergy	Drug allergy
ZV14y00	[V]Personal history of other specified drug allergy	Drug allergy
ZV14z00	[V]Personal history of unspecified drug allergy	Drug allergy
ZVu6M00	[X]Personal history of allergy to other antibiotic agents	Drug allergy
ZVu6N00	[X]Personal history/allergy to other anti-infective agents	Drug allergy
ZVu6P00	[X]Personal history/allergy/other drugs+biological substances	Drug allergy
ZVu6T00	[X]Personal history/allergy,other than/drugs+biological substance	Drug allergy
ZVu6i00	[X]Personal history of allergy to bisoprolol	Drug allergy
ZVu6o00	[X]Personal history of allergy to carvedilol	Drug allergy
ZVu6q00	[X]Personal history of allergy to nebivolol	Drug allergy
ZVu6r00	[X]Personal history of allergy to hair dye	Drug allergy
ZVu6s00	[X]Personal history of allergy to cosmetic products	Drug allergy
ZV14000	[V]Personal history of penicillin allergy	Drug allergy
14F1.00	H/O: eczema	Eczema
14M1.00	H/O: food allergy	Food allergy
ZV1B300	[V]Personal history of food induced anaphylaxis	Food Allergy
14B1.00	H/O: hay fever	Hay fever
14M..00	H/O: non-drug allergy	Other allegies
14M3.00	H/O: multiple allergies	Other allergies
14M2.00	H/O: plant allergy	Other allergies
ZV07100	[V]Desensitization to allergen	Other allergies
ZV15000	[V]Personal history of non-drug allergy	Other allergies
ZV58900	[V]Desensitization to allergens	Other allergies

3.E: Scientific Research Committee approval for study using the THIN database

3.F: TOTAL NUMBER OF CHILDREN AND GP PRACTICES WITHIN THE THIN DATASET. *(*population shown in 1000s)*

Year	UK (THIN) population*	WM (THIN) population*	UK (THIN) practices	WM (THIN) practices
1995	0.28	0.06	16	1
1996	4.45	0.44	69	9
1997	17.97	1.87	114	13
1998	39.36	4.29	157	20
1999	65.05	7.29	231	23
2000	99.57	10.95	300	26
2001	144.38	15.13	407	37
2002	198.29	19.97	461	42
2003	254.40	25.49	486	48
2004	311.61	31.40	529	51
2005	371.35	37.56	547	53
2006	428.60	43.92	572	53
2007	485.93	50.14	608	54
2008	543.13	56.15	626	54
2009	593.50	61.13	628	54
2010	627.29	64.94	623	54
2011	673.11	69.47	628	54
2012	714.48	74.32	615	53
2013	722.15	75.00	603	53
2014	617.51	58.96	494	37
2015	594.05	49.11	494	37
2016	176.89	11.86	400	24

3.G: CHANGES IN GENDER COMPOSITION OF CHILDREN WITHIN THIN DATASET OVER THE STUDY PERIOD

Year	Female(%)	Male (%)
2000	48.17	51.83
2001	48.38	51.62
2002	48.39	51.61
2003	48.44	51.56
2004	48.45	51.55
2005	48.53	51.47
2006	48.61	51.39
2007	48.62	51.38
2008	48.65	51.35
2009	48.69	51.31
2010	48.74	51.26
2011	48.85	51.15
2012	48.90	51.10
2013	48.89	51.11
2014	48.89	51.11
2015	48.91	51.09

4.A: ICD-10 AND OPSC4 CODES USED IN THE ANALYSIS

Group	ICD10 Code	Description
Allergic rhinitis	J301	Allergic rhinitis due to pollen
	J302	Other seasonal allergic rhinitis
	J303	Other allergic rhinitis
	J304	Allergic rhinitis, unspecified
Anaphylactic reactions	T780	Anaphylactic shock due to adverse food reaction
	T782	Anaphylactic shock, unspecified
	T805	Anaphylactic shock due to serum
	T886	Anaphylactic shock due to adverse effect of correct drug or medicament properly administered
Food allergies	K522	Allergic and dietetic gastroenteritis and colitis
	T781	Other adverse food reactions, not elsewhere classified
Angioedema	T78.3	Angioneurotic edema
Urticaria	L50.0	Allergic urticaria
	L50.5	Cholinergic urticaria
	L50.6	Contact urticaria
	L50.3	Dermatographic urticaria
	L50.1	Idiopathic urticaria
	L50.8	Other urticaria
	L56.3	Solar urticaria
	L50	Urticaria
	L50.2	Urticaria due to cold and heat
	L50.9	Urticaria, unspecified
	L50.4	Vibratory urticaria
Procedure codes (OPSC4)	X962	allergen immunotherapy drugs (Band1)
	Z516	Desensitisation to allergens
	X385	Subcutaneous immunotherapy
	X392	sublingual administration of a therapeutic substance

4.B: TOTAL NUMBER OF ADMISSIONS AS PER THE GEOGRAPHICAL REGION OF RESIDENCE (GOR)

REGION	FREQ.	PERCENT**
North East	3,706	4.52
North West	23,517	28.67
Yorkshire and The Humber	4,622	5.64
East Midlands	3,533	4.31
West Midlands	6,788	8.28
East	6,562	8
London	15,797	19.26
South East	12,147	14.81
South West	4,994	6.09
Wales	314	0.38

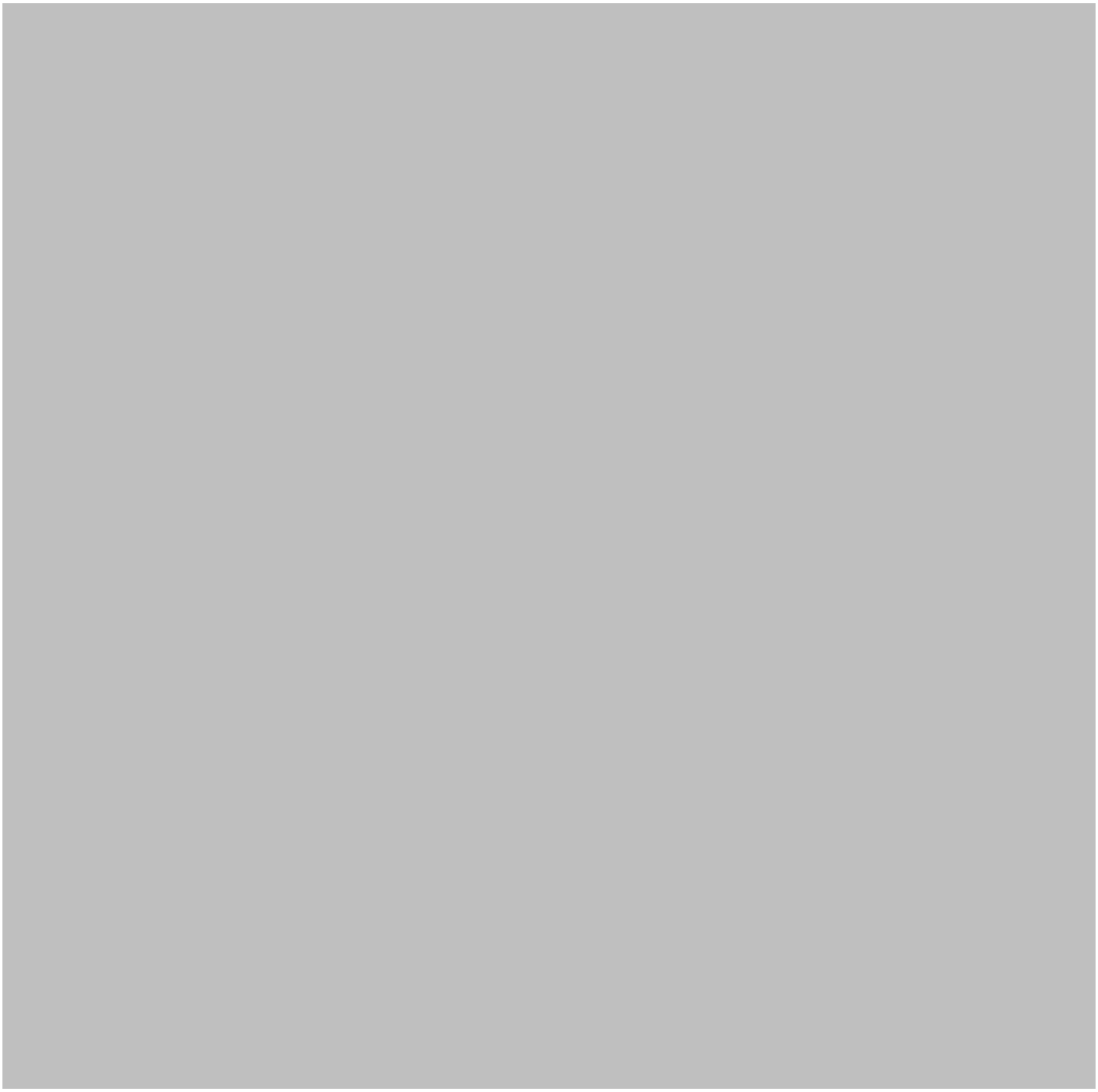
*figures may not add up to 100% due to rounding error
** Please note that these data are not corrected for the population statistics for these regions

4.C: PROPORTION OF CHILDREN (0-17YRS) WITHIN DIFFERENT AGE BANDS IN ENGLAND AND WM DURING THE STUDY PERIOD (2007-14)*

England census Proportion			
Year	**0-5yr**	**6-10yr**	**11-17 yr**
2007	29.13	28.00	42.87
2008	30.01	27.51	42.48
2009	30.69	27.38	41.93
2010	31.30	27.48	41.22
2011	31.10	27.44	41.46
2012	31.50	27.88	40.62
2013	31.52	28.60	39.88
2014	31.43	29.35	39.22
WM census Proportion			
Year	**0-5yr**	**6-10yr**	**11-17 yr**
2007	28.36	28.39	43.25
2008	29.11	27.78	43.11
2009	29.70	27.51	42.79
2010	30.10	27.53	42.37
2011	30.38	27.64	41.99
2012	30.77	28.07	41.16
2013	30.85	28.71	40.43
2014	30.80	29.42	39.78

*Data from ONS estimates

5.A: ETHICS APPROVAL FOR THE QUALITATIVE STUDY



5.B: PATIENT INFORMATION SHEET FOR QUALITATIVE STUDY

Paediatric Allergy Treatment Pathways in the West Midlands – Understanding Parent Experiences and Preferences

You have been provided with this information leaflet because the specialist treating your child's allergies felt that you may be a suitable candidate to take part in this study.

The chief investigator for this study is Dr Lavanya Diwakar. She is a researcher working at the Health Economics Unit at the University of Birmingham. This study will be a part of her PhD research.

Before you decide whether or not you want to take part, we would like you to understand why the research is being done and what it would involve for you. Please take the time to read this information carefully. Thank you for reading this.

You can contact Lavanya if you do not understand some of the information on this form or if you have any questions. Contact details are at the end of the form.

1. Purpose of the study

Allergy is a common problem in the UK. A large international study has shown that the UK has amongst the highest rates in the world for childhood asthma, eczema and hay fever. Allergic disease can significantly affect the quality of life of not only those suffering with the condition, but also that of their family members.

We want to find out from you, the parent of a child suffering with allergies, about problems, if any, that you may have experienced whilst availing NHS treatment for your child. We also want to know your opinion about the quality of services you have received.

Your answers are important to us as they will help us to understand the quality of care available in the West Midlands for children with allergies. We will share our results with those who make decisions about funding in the NHS in order to make a case for improving childhood allergy services locally.

2. Why have I been chosen?

We are inviting parents of over 18 years of age who can converse in English to take part in the study if their children have been diagnosed with an allergy at the specialist clinic.

We are trying to include parents of children with different allergies and age groups in order to get a broad understanding of the services in the West Midlands region.

3. **Do I have to take part?**

It is up to you to decide. Deciding not to participate or withdrawing from the study will not affect your/ your child's care in any way.

You can take your time to consider whether or not you want to participate in this study. You do not need to respond immediately and can take the documents provided with you if you prefer. We have provided a self-addressed envelope which can be used to post the consent form and the baseline form at a later date if you do agree to take part.

Even after signing the consent form, you are free to withdraw from the study at any time without giving us any explanation.

4. **What will happen if I take part?**

You will be asked to complete a consent form and another baseline form so that we can obtain your contact details. This should take no longer than 5-10 minutes to complete.

The researcher will then contact you to arrange for either a face-to-face interview or a telephone interview at a time that suits you. The face-to-face interviews can be carried out at the hospital, the University of Birmingham or at your home as per your convenience. The interview will take no longer than 45 minutes.

In order to make sure that we remember the information that we collect from all the different interviews, the interviews will be audio taped with your consent.

5. **What are the possible benefits of taking part?**

The information that we get from this study will be used to help understand your views and opinions on the current treatment pathways available for managing your child's allergy. This will be shared with those involved with designing NHS services and can help improve allergy services for children locally.

6. **Will my taking part in the study be kept confidential?**

Yes. Answers will be completely anonymous. With your permission we will audio record the information so that we are able to capture all your views and opinions as well as around 20 other people's views and opinions.

We may send the recorded interviews to an external company so that they can be transcribed into writing form. This external company will not have access to your personal identification data and is also bound by an agreement to keep the data confidential.

We will follow ethical and legal practice and all information will be kept confidential. We will not publish any information which could allow you to be identified.

7. **Who is organising and funding the study?**

The study is organised and sponsored by the University of Birmingham.

It is also supported by the Heart of England NHS Foundation Trust as well as the Shrewsbury and Telford Hospitals NHS Trust.

It is funded by the Wellcome Trust, which is a global charitable foundation that supports research worldwide

The Anaphylaxis campaign, a leading charity for individuals with serious allergies, also supports the study.

8. **Who has reviewed the study?**

This study has been reviewed and given a favourable opinion by an independent ethics organisation- the Newcastle & North Tyneside Research Ethics Committee -to protect your safety, rights, wellbeing and dignity.

Further approval has been obtained from the individual hospitals (i.e. Heartlands Hospital and Shrewsbury and Telford Hospitals) taking part in the study.

Researcher Contact Details:

Dr Lavanya Diwakar

Health Economics Unit

University of Birmingham

Edgbaston

B15 2TT

Email:

Tel:

Fax

Independent Contact (Not related to this study):

Shrewsbury Hospital:

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Level 2, Main Ward block

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Mytton Oak Road

Shrewsbury, Shropshire, SY3 8XQ

Tel:

Heartlands Hospital:

Patient Advise and Liaison Services (PALS)

Heartlands Hospital NHS Foundation Trust

Bordesley Green East

Birmingham, B9 5SS

Tel:

Study Supervisors:

Prof Tracy Roberts, Head of Health Economics Unit, University of Birmingham

Dr Carole Cummins, Senior Lecturer in Public Health, Epidemiology and Population Sciences, University of Birmingham

Prof Richard Lilford, Head of the Centre for International Research, University of Warwick

Clinical Collaborators:

Dr Scott Hackett, Consultant Paediatrician, Heartlands Hospital NHS Foundation Trust

Dr Martyn Rees, Consultant Paediatrician, Royal Shrewsbury Hospital NHS Trust

Supported by:

The anaphylaxis campaign; www.anaphylaxis.org.uk

CONSULTANT NAME: CONSULTANT TEL:

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET.

5.C: PARTICIPANT CONSENT FORM

Paediatric Allergy Pathways in the West Midlands- Parent Experiences

Participant Consent Form

Please initial each box to confirm consent

I confirm that I have read and understood the information sheet *(Version 3.2, Date: 25.06.2014)* for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

I agree to my sample/data being shared with collaborating institutions, NHS Trusts, Universities and Commercial partners within and outside of the UK now and in the future. ☐

I understand that my sample/data will be completely anonymised and no identifiable information will be shared. ☐

I understand the data collected during the study may be looked at by regulatory authorities where relevant in this research. I give permission for these individuals to have access to these data. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

I give permission for the study researchers to contact me by telephone to arrange an interview ☐

I give permission for the interviews to be tape-recorded. ☐

I understand that the information will be used for research only and that I will not be identified in any way in the analysis and the reporting of results. ☐

I understand what is involved and agree to take part in this study. ☐

_____ _____ _____

Name of participant Date Signature

Name of Consent Taker Date Signature

5.D: DEMOGRAPHIC DETAILS QUESTIONNAIRE

Interview study: Parent experiences with allergy services for children in the West Midlands

Thank you for agreeing to take part in this study. We want to find out about your experiences with accessing allergy services for your child. Participation in this study does not affect the care provided to your child in any way and you are free to withdraw from it at any time without providing any explanation.

Details regarding the study are provided in the information sheet which would have been given to you. Please feel free to contact the researcher (Dr Diwakar) if you have any further details that you may wish to clarify.

Please complete this questionnaire after you have read the information sheet carefully and send it to the researcher using the self-addressed envelope provided. The researcher will be in touch with you within 7 days after that to confirm with you a date, time and place for a detailed interview. This initial call will take not more than 5 -10 minutes.

The detailed interview can be carried out at the hospital, your home or on the telephone as per your preference. The interview will last between 45 and 60 minutes.

1. *Your name*:
2. *Your age group (please circle as appropriate):*

   <18 yrs; 19-25 yrs; 26-40 yrs; 41-55 yrs; >55 yrs
3. *What allergies does your child have?* .....
4. *How old is your child?* ..... *yrs*
5. *Please provide your contact details in order that the researcher may contact you*:*

   Mobile:

   Landline:

   Email:

   *(*We will call you on your mobile number unless you prefer that we call another number. Other details will only be used if we are unable to contact you for any reason. We will not share these details with anyone and this form will be destroyed once the main interview has been completed)*
6. *When would it be suitable for us to contact you for the initial 5-10 min call?*

   Day (circle one or more days that suit): Monday/ Tuesday/ Wednesday/ Thursday/ Friday Time: .....

I give permission for Dr Diwakar to contact me regarding this study using the details provided

Signature:

Name (Print): Date:

5.E: INTERVIEW TOPIC GUIDE

Parent experiences of paediatric allergy pathways in the West Midlands

(Note – the points below will act as a guide to make sure all relevant topics are covered. The interview will be semi-structured and take form of a 'guided conversation', hence the points may not be covered in this specific order etc.)

- Check that this is a good time? It won't take long – about 45 minutes.
- Thank you for agreeing to talk to me today. I just wanted to start off by talking to you again about the study – is that ok?
- I'm Lavanya, a researcher at the University of Birmingham. We are carrying out research looking at parent's experiences with getting health care for their children's allergies. We are talking to around 20 parents who have accessed the allergy clinics for their children in order to find out what their experiences have been like. The findings of the research will be used to help improve services.
- All the information we are collecting will be anonymous. Just to confirm that I am an independent researcher, employed by the University of Birmingham, and nothing you say will have any effect on your care at the hospital or GP surgery.
- Most of the issues that we discuss should be straightforward but it is possible that you may feel uncomfortable talking about certain things. If you feel you would rather not answer any of the questions you can tell me and we can skip to something else. If you want to finish our conversation at any time – that is absolutely fine.
- The results of the study will be used for research, to understand people's experiences of accessing allergy services. We will share some overall findings with the centre and publish our results in academic journals, but no information will be published which would allow individuals to be identified.
- Are you happy to talk to me today to help with this study?
- I would like to tape record the interview – this is so that I can concentrate on what you are saying and so that I can examine what people have said in more detail afterwards. Only people in the research team at the University of Birmingham will listen to the recordings. Is this ok?
- If you want to withdraw from the study for any reason, you can do so within 2 weeks of this interview. We will ensure that the details relating to this interview are removed and destroyed.
- Do you have any questions about the study?
- Are happy to continue with the interview?

1. **Warm up**

- Just to start off, can you tell me a bit about yourself? We don't need to know any personal information, but it would be good to know whether you are working, not working, training, studying, looking after family etc.?
- About your child- how old is he/ she? Is he/she in school? Siblings?

2. **Allergies**

- Tell me a little about your little ones allergies.

  (when diagnosed, by whom, how serious)

- At the time that this reaction occurred, how did you feel? (in control or not?)
- Any help with managing these?
- Why did they feel the need for medical help?

3. **Primary care**

- How easy was it to see your GP?
- How did your GP treat the condition? (were they understanding/ dismissive/ helpful)
- Did you see anyone else at the surgery? (practice nurse/ dietician etc)
- Was it useful to see the GP? (more control?/ better understanding?)
- Did you feel satisfied with the appointment?

4. **Referral to secondary care**

- Did your GP offer to refer you on?
- Why did you feel the need to go to secondary care?
- How easy was it to get an appointment for the allergy clinic?
- How long did you have to wait?
- Was it easy to get to the clinic?
- How far away is the clinic from your home?
- Did you have any other problems? (parking?)

5. **Specialist clinic**

- Did you get seen on time?
- What did you think about the clinic? Was it pleasant? Were the staff helpful?
- Who saw you? (nurse/ doctor)
- Did you feel that you had sufficient time with the specialist?
- What was your appointment like?

- Did he/ she have any tests?
- Was it useful?
- Were you satisfied with the appointment?

6. Advantages of seeing practitioners for allergy

- Do you feel that you have gained anything from
    - The GP appointment
    - The specialist appointment
- Could you have managed without seeing them?
- Have you seen any other practitioners for your child's allergy?
    - If yes, was it useful and how?

7. General effects of the allergy

- How has your child's allergy affected life at home/ school/ play etc?
- Have you told other family members about the child's allergy? What is the reaction?
- How do you see the future for your child in the context of his/ her allergies?
- Does it worry you?
- Cost of food/ allergen free products
- Other costs to the household

8. Services for allergy

- How do you think services for allergy can be improved? (are the services ok the way they are now/ are you happy with them?)
- Ask specifically about primary care
- Do you think availability of better information will help?
- What do you think of the current food labelling systems?

9. Closing, thanking and signposting

- Did you have anything else you wanted to tell me about?
- It's been so helpful talking to you today. Just to stress that all the information you have given us will be anonymous – we don't have any personal information about you. All the information will be kept confidential and secure. We will share some general results with the centre and publish our findings to help improve services. But we won't publish any information which could identify someone.

6.A NGENE CODING AND OUTPUT FOR FINAL DCE

```
Design
;alts = alt1, alt2
;rows=18
;orth = seq
;model:
U(alt1) = b1+ b2* person[0,1,2]+ b3*info[0,1,2] + b4*support[0,1] + b5*wait[0,1,2]+ b6* cost[0,1,2] /
U(alt2)= b2*person+ b3*info + b4*support+ b5*wait + b6*cost$
```

Design

Choice situation	alt1.person	alt1.info	alt1.support	alt1.wait	alt1.cost	alt2.person	alt2.info	alt2.support	alt2.wait	alt2.cost
1	0	0	0	0	0	1	0	0	0	1
2	1	1	0	1	1	2	0	1	2	1
3	2	2	0	2	2	2	2	1	0	1
4	2	1	0	1	2	0	1	0	2	1
5	0	2	0	2	0	0	1	1	0	2
6	1	0	0	0	1	2	1	1	0	0
7	1	2	0	0	2	2	1	0	1	2
8	2	0	0	1	0	1	2	0	0	2
9	0	1	0	2	1	1	1	1	2	0
10	1	1	1	2	0	2	2	0	2	2
11	2	2	1	0	1	1	2	1	1	0
12	0	0	1	1	2	0	2	0	2	0
13	2	0	1	2	1	2	0	0	1	0
14	0	1	1	0	2	0	2	1	1	1
15	1	2	1	1	0	0	0	0	0	0
16	0	2	1	1	1	1	0	1	2	2
17	1	0	1	2	2	1	1	0	1	1
18	2	1	1	0	0	0	0	1	1	2

6.B: ETHICS APPROVAL FOR FINAL DCE SURVEY

6.C: EFFECTS CODING VERSUS DUMMY CODING IN DCE

Effects coding and dummy coding are two commonly used methods for categorical coding within a DCE. In both of these approaches, one level within each attribute is used as the reference point for estimating the utility values for the other levels[223].

In the example shown below (Table 6-), the nurse specialist level is the omitted variable (or the reference variable). In dummy coding, the reference variable is given a value of 0 as default. The other levels within the attribute are assigned a value of 1 when present within the choice set and 0 when a different level is present in the corresponding choice set. However, this type of coding can cause an issue with identification during analysis since it does not differentiate between the utilities of the reference variable and the omitted variables. Effects coding provides a way to resolve this problem by assigning the reference variable a value of -1[276] whist assigning values of 0 and 1 to the omitted and non-omitted variables respectively.

Table 6-A: An example of dummy and effects coding within DCE

	A	B
Clinician seen	Consultant- no allergy training	Consultant- allergy trained

Attribute	Levels	Dummy coding		Effects coding	
		Choice A	Choice B	Choice A	Choice B
Clinician seen	Nurse specialist (omitted variable)	0	0	-1	-1
	Consultant- no allergy training	1	0	1	0
	Consultant Allergy trained	0	1	0	1

Both types of coding analysis yield the same information regarding the difference in utility estimates between the levels of the attribute. However, whereas effects coding estimates the coefficient relative to the mean attribute effect, dummy coding estimates the strength of preference of a given level relative to the omitted level[277]. Thus, in dummy coding (and not

in effects coding), the statistical tests for significance are a reflection of the difference in preference weights between the omitted and the comparator levels[277].

6.D: EXAMPLES OF FEEDBACK - PILOT SURVEY 1

05 December 2016 11

Dear Lavanya,

Sorry for late reply. The survey looked great, it was very easy to understand and the explanations were well done.
Just wondering if there would be someway of rephrasing the line " All these associated problems can make looking after some of these children a little complicated", maybe "All of the associated problems can make looking after children more complicated".
Also for the whether a patient would see a doctor or nurse, is the doctor specifically an allergy specialist or paediatrician or does it mean it could be either?
And last comment, for the type of information available regarding allergies in children, maybe just combine the sentences for each bullet point i.e. 1. No information: No specific information provided. Parents were expected to obtain information by themselves either from the internet or from other parents, instead of two separate paragraphs.
Not sure if these comments will be of any help, just what I picked up on. Thanks again for sending me on the survey.

P1 Q1 There is a type – we willpresent
Q2 I found options 2 & 3 difficult to read and distinguish between. I think the wording could be improve and maybe the order changed i.e 3 before 2
Q3 The question maybe be better as 'Who would you prefer **your child** to see?'
Q3 Answer 4 - 'No-one I do not like going to hospital' seems an odd response – is it about the adult or the child?
Q4 Can more than one answer be given. I wanted to say written and verbal – needs to be made clearer
Q5 The questions were slightly unclear:

- Being seen by different specialists at the same time – maybe better as Being seen by different specialists during the same appointment or visit
- Different specialists at **separate** appointments
- I prefer seeing GP only – what about an option to say I prefer seeing the nurse or consultant only

Q6 May be better to replace 'person' with 'professional'?

I found the discrete choice section clear but I am familiar with this type of questioning so may not reflect a lay view.

6.E: EXAMPLES OF FEEDBACK - PILOT SURVEY 2

Hi Lavanya,
I've just done the survey. Just a few comments - feel free to ignore anything/everything.

(1) I found it difficult to remember that I was the parent of Jill, who had eczema (I think?) - I wonder if repeating the information (or a picture) on each page might help? I think I did answer some questions as if it were my own children, who don't have eczema.

(2) I've no idea if I was consistent with the out of pocket expenses questions, but I think I had problems conceptualising what they were for. I would have found it easier to be asked to pay £50/£100 etc for the appointment itself, but I would have answered it differently. In reality, when I had appointments for myself that I needed the kids in nursery for, I just paid the amount, and didn't add up extra food etc as well. Not sure I'm explaining myself very well here, sorry!

(3) Sorry to be pernickety but, hey, I was an editor. It would probably benefit from being edited and checked for consistency (upper case None alongside lower case none shrieked a bit at me, but there were other examples).

(4) There were quite a lot of scenarios....

(5) The questions at the end about my child's health and GP visits were difficult to answer because I've got two - but presumably this will go to people with a particular child that uses the clinic?

(6) Trivial, but the page numbering being so nearly the same as the question numbering was a little jarring.

Hi Lavanya
I have just taken the survey and have a few comments:

Info to participants at start does not mention anonymity, confidentiality, how you will store the data etc , which univ is supervising your research etc
Should the demographics and info about their children come first to make it clear it is about their experience and their views . I think some explanation that we are interested in your views whether or not you have experience of alllergy services would be good and some explanation as to how this research may impact on the way services are designed in the future.
Also my ethnicity is white british - my children are mixed race - black british

Not sure what red asterik by each question is about
Section 5 - are you saying parents either get 1, 2 **or** 3 at moment ? why is 3 in bold and others not ?
Additional services - do you mean services or support - may need a consistent word here
Section 7 - not sure it is useful to mention charging - as the focus of the question is out of pocket expenses - does raising the issue of NHS charges raise unnecessary concerns
Would be helpful of sections and question numbers corresponded - bit confusin that section 7 contains question 6- but may not be a big issue

Section 8 has no heading

There are far too many questions on choice of clinic - I was getting really frustrated by the end . I understand the need for these multiple options but it does take a long time to complete and there is a danger that towards the end people will just not read and put any option down
I am not sure how the factors which influence parent's choices will emerge from this ? I know you will get preferences but there are key factors which influence this and which perhaps you could ask about _ eg how ill Jill is, how much time she has missed from nursery , how much time the parent has missed from work already, their income level , the flexibility of their employer, what experience they have had of different NHS professions to date and their views about them and I am sure many more .

Hi Lavanya,

Thanks for the invitation to pilot your DCE. I have never done one before but I have heard of them before and understand a little about why you might do one so I hope that my comments are helpful.

My main comment is that it takes a lot of time and mental effort to complete (even for a PhD student, so I am not sure how others will experience it), though I am not sure whether the market research company will help people with this.

Also that the scenarios seem really repetitive, even though I know why. I wasn't expecting so many so I got a little weary after about 12 or so. I wonder if it would help to give a little warning of this in the screen before the choices begin, with an indication of how many there will be and why.

Also... this might be something that you have already given a lot of thought to but I can't really imagine a scenario where you would get no information at all at an appointment (perhaps not enough, or not comprehensible, but I can't imagine getting none), so this seemed a little odd in the DCE. I wonder whether pitching verbal and written, as well as both together, against each other in more scenarios would be useful.

APPENDIX 6.F: DCE RESULTS (SUBGROUP ANALYSIS)

Attribute	Child with allergy[$]	High income^	Has consulted secondary care [++]
Person			
Nurse specialist (allergy trained)	(Baseline)	(Baseline)	(Baseline)
Consultant-no allergy training	-0.99***	-1.11***	-1.11***
Consultant - allergy trained	0.29***	0.40***	0.38***
Information			
Improved NHS choices website	(Baseline)	(Baseline)	(Baseline)
Verbal information	-0.34***	-0.43***	-0.43***
Detailed written information	-0.25***	-0.32***	-0.32***
Support			
No additional support	(Baseline)	(Baseline)	(Baseline)
Additional support available	0.11***	0.14**	0.15***
Waiting time			
8 weeks	(Baseline)	(Baseline)	(Baseline)
12 weeks	-0.39***	-0.52***	-0.51***
18 weeks	-0.69***	-0.86***	-0.85***
Out of pocket costs			
£25	(Baseline)	(Baseline)	(Baseline)
£50	-0.33***	-0.43***	-0.42***
£100	-0.42***	-0.54***	-0.52***
Constant	0.113[#]	0.72***	0.71***

[$] Child currently has either eczema, asthma or allergy; ^ Income of £43,000 or more; Respondents who did not provide an income level (14.3%) were excluded from the analysis.[++] Child seen by consultant in the last 12 months for any condition; ***p<0.0001; **p<0.001; [#]p=0.01

APPENDIX 6.G: FINAL DCE QUESTIONNAIRE (.pdf attached)

UNIVERSITY OF BIRMINGHAM

PARENT PREFERENCES FOR PAEDIATRIC ALLERGY SERVICES

This research study aims to inform commissioners and those in charge of planning NHS services what parents in the West Midlands prefer with regards to these services.

The results of this research will also be included in the PhD thesis of Dr Lavanya Diwakar, a researcher based at the Health Economics Unit within the University of Birmingham.

We will be presenting the results of this survey at some seminars or conferences and may also publish the results in medical journals. The survey should take no more than 10-15 minutes to complete.

Please be assured that your responses to this survey will be kept confidential and anonymous. Your identity will remain confidential and your answers will only be reported in the aggregate (that is, alongside answers from other respondents).

You can stop answering the survey at any time. However, only when you complete this survey, you will become eligible to be included in a lucky draw to win amazon vouchers worth £25.

If you have any questions or queries regarding this survey, you can contact Dr Diwakar on [redacted] You can also contact the M·E·L Research team [redacted] for more information.

Please note that if you change your mind once your answers have been submitted to us, you can contact M·E·L Research at [redacted] to withdraw your responses for up to one week after you have completed the survey.

Thank you for your participation.

APPENDIX 7.A: SYSTEMATIC REVIEW PUBLICATION

Open Access Research

BMJ Open

Systematic review of pathways for the delivery of allergy services

Lavanya Diwakar,[1] Carole Cummins,[2] Richard Lilford,[3] Tracy Roberts[1]

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ABSTRACT

Objectives: The incidence and prevalence of allergies worldwide has been increasing and allergy services globally are unable to keep up with this increase in demand. This systematic review aims to understand the delivery of allergy services worldwide, challenges faced and future directions for service delivery.

Methods: A systematic scoping review of Ovid, EMBASE, HMIC, CINAHL, Cochrane, DARE, NHS EED and INAHTA databases was carried out using predefined inclusion and exclusion criteria. Data on the geographical region, study design and treatment pathways described were collected, and the findings were narratively reported. This review followed the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines.

Results: 205 publications were screened and 27 selected for review. Only 3 were prospective studies, and none included a control group. There were no eligible publications identified from North America, Africa, Australia and most parts of Asia. Most publications relate to allergy services in the UK. In general, allergy services globally appear not to have kept pace with increasing demand. The review suggests that primary care practitioners are not being adequately trained in allergy and that there is a paucity of appropriately trained specialists, especially in paediatric allergy. There appear to be considerable barriers to service improvement, including lack of political will and reluctance to allocate funds from local budgets.

Conclusions: Demand for allergy services appears to have significantly outpaced supply. Primary and secondary care pathways in allergy seem inadequate leading to poor referral practices, delays in patient management and consequently poor outcomes. Improvement of services requires strong public and political engagement. There is a need for well-planned, prospective studies in this area and a few are currently underway. There is no evidence to suggest that any given pathway of service provision is better than another although data from a few long-term, prospective studies look very promising.

Strengths and limitations of this study

- The literature review was carried out using eight major databases and reporting followed the PRISMA guidelines.
- This is comprehensive review of all the published reports and journal articles on allergy services.
- No eligible publications were identified from large geographical areas such as North America, Africa, Australia and most of Asia; most publications were UK based.
- Service pathways for allergy and eczema were considered in the review.

INTRODUCTION

The incidence and prevalence of allergic diseases has been steadily increasing globally.[1] It is recognised that there has been an increase in the prevalence of allergies in children and young adults with each passing decade.[2] Despite this increasing need, allergy services have not improved worldwide.[3] It is now well established that developed countries bear a higher burden of allergic disease.[1 4–6] However, services rendered to the affected individuals in these higher income countries remain inadequate with deficiencies in primary and secondary care provision.[5 7] The picture is similar across many countries with long waiting times for specialist appointments and wide heterogeneity in provision of primary care and specialist services.[7 8] In addition, the growing incidence of serious allergic manifestations such as anaphylaxis[9–12] as well as that of individuals with multiple, complex allergies[13] has prompted calls for improved services worldwide.[3 13]

The UK has one of the highest rates of allergy and related diseases in the western hemisphere[1] with a steady increase in the prevalence, severity and complexity of allergic disease in the last two to three decades.[2 14–17] It is estimated that 30% of all adults and 40% of children in the UK will be affected by allergy-related conditions.[18] Nevertheless, allergy services have remained 'woefully poor'[18] with very limited and patchy specialist service availability. This shortfall in service availability and the inherent heterogeneity of limited available services has been the focus of multiple expert body reviews in the UK, which have called for

APPENDIX 7.B: ADRENALINE AUTOINJECTOR PUBLICATION

Research

Lavanya Diwakar, Carole Cummins, Ronan Ryan, Tom Marshall and Tracy Roberts

Prescription rates of adrenaline auto-injectors for children in UK general practice:

a retrospective cohort study

Abstract

Background
Adrenaline auto-injectors (AAI) should be provided to individuals considered to be at high risk of anaphylaxis. There is some evidence that the rate of AAI prescription is increasing, but the true extent has not been previously quantified.

Aim
To estimate the trends in annual GP-issued prescriptions for AAI among UK children between 2000 and 2012.

Design and setting
Retrospective cohort study using data from primary care practices that contributed to The Health Improvement Network (THIN) database.

Method
Children and young people aged between 0–17 years of age with a prescription for AAIs were identified, and annual AAI device prescription rates were estimated using Stata (version 12).

Results
A total of 1.06 million UK children were identified, providing 5.1 million person years of follow-up data. Overall, 23 837 children were deemed high risk by their GPs, and were prescribed 98 737 AAI devices. This equates to 4.67 children (95% confidence interval [CI] = 4.66 to 4.69), and 19.4 (95% CI = 19.2 to 19.5) devices per 1000 person years. Between 2000 and 2012, there has been a 355% increase in the number of children prescribed devices, and a 506% increase in the total number of AAI devices prescribed per 1000 person years in the UK. The number of devices issued per high-risk child during this period has also increased by 33%.

Conclusion
The number of children being prescribed AAI devices and the number of devices being prescribed in UK primary care between 2000 and 2012 has significantly increased. A discussion to promote rational prescribing of AAIs in the NHS is needed.

Keywords
allergy; adrenaline; anaphylaxis; database; general practice; prescriptions; primary health care.

INTRODUCTION

Anaphylaxis is a 'serious allergic event that is rapid in onset and may cause death'.[1] Pre-filled adrenaline auto-injectors (AAI) are provided to individuals at high risk of anaphylaxis for emergency self-administration, to prevent worsening of early symptoms of anaphylaxis.[2]

Since their introduction into the UK in March 1996,[2] prescription rates of these devices in the community has increased exponentially.[3] The current UK and European paediatric guidelines suggest that a child with minor reactions to peanuts or tree nuts could be prescribed an AAI.[4,5] Others argue that the devices should only be prescribed to children who have experienced moderate or severe allergic reactions.[6] The British Society of Allergy and Clinical Immunology (BSACI) has also laid down guidance for the prescription of these devices.[7] However, it is well recognised that reaction history to an allergen does not predict the severity of subsequent reactions.[8,9] A recent survey of UK physicians showed that there was a great deal of heterogeneity in the prescription of these devices.[10]

Although previous publications from England and Australia have documented the increase in the number of AAIs being prescribed to children in the community,[3,11] the true extent of this in the UK has not yet been explored.

METHOD

The authors used data from The Health Improvement Network (THIN). The database currently includes information from 587 primary care practices across the UK, covering more than 12 million patients (about 3.6 million active patients), who represent about 6% of the entire UK population.[12] These data are representative of the UK population by age, sex, medical conditions, and death rates adjusted for demographics and social deprivation.[13] Participating practices use Vision software to maintain patient records and issue prescriptions. Prescription data from THIN have been previously validated for pharmacoepidemiological research.[14]

Study population

All children and young people aged 0–17 years registered for a minimum of 1 year between 1 January 2000 and 31 December 2012 in primary care practices contributing to the THIN database were included in the analysis. The children contributed to the dataset from the time of their registration with the practice until the earliest of their 18th birthday, transfer to another surgery, death, or last data

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